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ABSTRACT

Presented are the proceedings of a conference on Understanding the Needs of Deaf-Blind Children in Isolated Areas, sponsored by the Southwest Region Deaf-Blind Center, April 29-May 1, 1976 in Honolulu, Hawaii. Talks include "Psychological Assessment" (C. Groves), "Visual Assessment and Training of the Deaf-Blind Child" (R. Funderburg), "Auditory Evaluation of the Deaf-Blind and Multihandicapped Child--Implications for Training" (B. Franklin), "Classroom Management" (M. Dronek), "Speech and Language Evaluation of the Deaf-Blind and Multihandicapped Child--Implications for Training" (B. Franklin), "Prevocatinal Training" (P. Small), "Home Programming in Isolated Areas" (D. Young), "Atypical Development" (C. Groves), "Creative Play--A Vital Learning Experience for the Young Deaf-Blind Child" (C. Stensrud), "The Deaf-Blind Child--A Sexual Being" (J. Neff), and "Parent Effectiveness" (M. Sturrock). (DLS)

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Proceedings

Understanding the Needs of Deaf-Blind Children in Isolated Areas

Prepared under the direction of

William A. Blea, Project Director, Southwestern Region Deaf-Blind Center, California State Department of Education

and

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Preface

This three-day conference was sponsored by the Southwest Region Deaf-Blind Center and hosted by the Easter Seal Society of Oahu, Inc., Honolulu, Hawaii, from April 29 through May 1, 1976. The purpose of the conference was to acquaint professional personnel with the methodology available for use with deaf-blind children found in the isolated areas of the United States.

One may ask what the difference is between the deaf-blind child in the isolated area and the deaf-blind child in the urban area? Usually, the child in the isolated area is not in a program for the deaf-blind. This child most often does not have a peer to interact with. The deaf-blind child in the urban area, however, receives daily stimulation through participation in classroom activities.

The regional centers have a responsibility to provide stimulation and encouragement to the teachers and aides and parents of the deaf-blind children in isolated areas. The proceedings of this conference are intended to provide individuals who work with these children with some helpful information and to encourage them to contact their regional center office when assistance is needed.

WILLIAM A. BLEA
Project Director
Southwestern Region Deaf-Blind Center

Agenda for Workshop

Sheraton Moana Hotel
Honolulu, Hawaii

Thursday, April 29, 1976

8–8:30 a.m. ..... Registration

8:30 a.m. ..... Conference Opening

Call to order:
Betsy Cotter, Coordinator
Deaf-Blind Project
Sultan Easter Seal School
Honolulu, Hawaii

Welcome:
William A. Blea, Ed.D.
Project Director
Southwestern Region Deaf-Blind Center
Sacramento, California

Panel presentation on needs identification in the Pacific:
Betsy Cotter, Coordinator
Deaf-Blind Project, Hawaii

Dennis McCrea, Program Director
Special Education, American Samoa

Elsa Thomas, Coordinator
Special Education, Trust Territory

10–10:15 a.m. ..... Break

10:15–11:15 a.m. ..... Psychological Assessment
Cathy Groves, Instructor
San Francisco State University

11:15 a.m.–12:15 p.m. ... Visual Assessment and Training
Ruth Funderburg, Assistant Professor
Department of Special Education
University of Hawaii at Moana

12:15–1:15 p.m. ..... Lunch

1:15–2:15 p.m. ..... Audiology
Barbara Franklin, Coordinator
Deaf-Blind Program
Department of Special Education
San Francisco State University

2:15–3 p.m. ..... Classroom Management
Margo Dronek, Curriculum Specialist
Southwestern Region Deaf-Blind Center

3–3:15 p.m. ..... Break

3:15–4 p.m. ..... Small Group Discussions

4 p.m. ..... Summary of Discussions

Friday, April 30, 1976

8:30–8:45 a.m. ..... Opening
William A. Blea

8:45–9:45 a.m. ..... Speech
Barbara Franklin

9:45–10:45 a.m. ..... Prevocational Training
Paul Small, Prevocational Specialist
Southwestern Region Deaf-Blind Center

10:45–11 a.m. ..... Break

11–12 noon ..... Home Programming in Isolated Areas
Dottie Tehan Young
Outreach Teacher
Navajo Tribe
Gallup, New Mexico

12 noon–1 p.m. ..... Lunch

1–2 p.m. ..... Atypical Development
Cathy Groves

2–3 p.m. ..... Recreation
Carol Stensurd, Assistant Professor
Recreation Education Department
California State University at Chico

3–3:45 p.m. ..... Total Communication
Paul Starkovich, Program Specialist
Southwestern Region Deaf-Blind Center

Saturday, May 1, 1976

8–8:15 a.m. ..... Registration

8:15–8:30 a.m. ..... Opening
William A. Blea

8:30–9 a.m. ..... Self-Help Skills
Margo Dronek

9–9:30 a.m. ..... Mobility
Sam Fisk
Orientation/Mobility Instructor, Hoopono
Services for the Blind Branch
Department of Social Services and Housing

9:30–9:45 a.m. ..... Break

9:45–10:30 a.m. ..... Audio Visual Techniques
Mary Tarling, Program Specialist for
Severely and Multiply Handicapped
Los Angeles County Schools

Richard Johnston, Media Specialist
Southwestern Region Deaf-Blind Center

10:30–11:30 a.m. ..... Adolescence and Maturity
Jan Neff, Teacher
Growth and Development: Crafts
California School for the Blind, Berkeley

11:30 a.m.–12:30 p.m. ..... Lunch

12:30–1:15 p.m. ..... Parent Effectiveness
Marilyn Sturrock
Parent of Deaf-Blind Boy

1:15–2 p.m. ..... Panel Discussions
Center Staff and Last Day Speakers

2 p.m. ..... Conference Summary and Closing

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Introduction

Presented by William A. Blea
Southwestern Region Deaf-Blind Center

This first Deaf-Blind Pan-Pacific Workshop is offered by the Southwestern Region Deaf-Blind Center in cooperation with the Easter Seal Society of Oahu to assist professionals and parents in the delivery of quality services to severely multiply handicapped deaf-blind children and their families.

Like all meetings between people sharing a common concern, this conference can be a source of vital information on meeting the needs of the severely multiply handicapped deaf-blind children. But within the short span of one conference, we cannot give you all the answers you need and want. We can meet your needs only if you express them; we are not omniscient. Your input is necessary to meet the needs of these children.

This conference is only a beginning.

Your needs may be quite unique, and we want to accommodate the services we offer to those expressed needs. Our purpose is not to enforce any methodology or technique but to serve multiply handicapped deaf-blind children.

Change is inevitable over both space and time, and the Southwestern Region Deaf-Blind Center strives to accommodate movement in both dimensions. Established in 1969, the Center has served the deaf-blind population and worked to meet the changing needs of these children as they matured from infancy to teenagers, and for some, into adulthood. The Center also serves deaf-blind children over a diverse geographical area, including American Samoa, Arizona, California, Guam, Hawaii, Nevada, and the Trust Territory of the Pacific Islands, as well as the Navajo Indian Nation.

The Southwestern Region Deaf-Blind Center, operating under Title VI-C funds, and the Bureau of Education for the Handicapped, Office of Education, Department of Health, Education, and Welfare in Washington, D.C., is designed to provide three basic types of services to severely multiply handicapped deaf-blind children and their families: (1) diagnosis and evaluation of the children by medical, educational, and psychological specialists or by other specialists as needed; (2) education; and (3) counseling and other supportive services to the family.

In addition to these basic services, the Center also develops or assists in the development of curriculum materials and programs for the severely multiply handicapped deaf-blind; it encourages colleges and universities to conduct professional and paraprofessional training programs and to develop continuous inservice training for personnel who are already working with the deaf-blind; it assists both public and private agencies in planning, developing, and providing appropriate services; and it participates in community, state, regional, and national organizations with the objective of sharing information, contributing knowledge, and developing receptive public attitudes with respect to services for multiply handicapped deaf-blind children.

While the services and training we provide are designed primarily for the deaf-blind, the techniques and programs developed to serve these, the most severely handicapped of children, will also benefit children with other, less handicapping conditions.

A total of 1,070 deaf-blind children have been located within the Southwestern Region to date. Approximately 15 percent of these children live in the Pan-Pacific area. Search projects within this area are still underway, so this number may yet increase. The Southwestern Region Deaf-Blind Center is assisting American Samoa, Guam, Hawaii, and the Trust Territory to fulfill their commitments to these multiply handicapped deaf-blind children in a number of ways. In the Trust Territory, for example, a search and identification project has been conducted. To date, 108 multiply handicapped deaf-blind children have been located in five of six districts.

Inservice training for teachers in the Trust Territory was provided during a four-week summer session last year, and two teachers from the Trust Territory are currently attending the National Leadership Training Program at Northridge. After

this conference is over, another seven teachers will be going to the California School for the Blind in Berkeley for additional training.

In Guam we have funded two classroom programs and provided inservice training to two teachers through our Special Study Institute for Teachers and Administrators. Through coordinated efforts of a number of agencies, one deaf-blind child from Saipan was sent to Hawaii for assessment and corrective surgery.

American Samoa had an established program for deaf-blind children but needed a van to provide transportation to and from school, which we were able to provide for them. Our job is not to replace existing programs but to supplement them as needed to make existing services more effective.

In Hawaii, we have been funding classroom programs for six years. The state of Hawaii is funding additional classroom programs. Home services are provided by a visiting social worker to deaf-blind children too young for classroom programs. A summer camp provides additional training experiences for children and provides respite care for parents. Several parents and teachers from Hawaii attended our Special Study Institute on the mainland, and the parent group made a full report to those parents not able to attend.

In the future we plan to provide workshops throughout the entire region. If funding allows, two of these workshops will be held in the Pan-Pacific region.

We publish two bimonthly newsletters to keep you informed on training programs, jobs, nutrition, medicine, psychology, classroom projects, legislative and financial news, newly developed resources, and helpful information for parents to use at home. Thy National Parents Exchange keeps parents throughout the United States and its territories informed on matters of interest relating to their deaf-blind children, and our regional newsletter for professionals, the *Interchange*, keeps you up-to-date on what is happening within our area. If you are not receiving these newsletters, write to me in Sacramento, and I will see that you are put on the mailing list. We also have a bibliography of materials available from all the regions included in your information packet. These materials are also available upon request from the Center.

To provide direct technical assistance and to help you solve specific problems that cannot be dealt with in large group meetings, we have scheduled regular visits by our consultants. They will be traveling throughout the Pacific area on a regular basis to provide you with direct, immediate personal service to meet your needs in working with these children.

Let me remind you, however, that to provide services for the severely multiply handicapped deaf-blind children in the Pan-Pacific area—services to fulfill your greatest needs, that are appropriate to your needs—we must hear from you both as groups and as individuals. Let us know what you need.

Providing services means allocating funds, and funding takes time. To be funded, programs must be planned anywhere from one year to one and one-half years in advance. We will try to meet your needs and objectives as best we can. But this must be done on a long-range basis. It often seems that change occurs slowly. But change does occur, and we will do our best to be responsive to your needs. Like a child, one must first crawl, then walk, and finally run. Nothing happens all at once.

Our ability to accommodate our programs and services to fulfill your needs will be only as good, and as successful, as the people who support us. We depend on all of you—teachers, parents, aides, administrators—to make your needs known to ensure the best of all possible services for the children you care for.

Psychological Assessment

Presented by Cathy Callahan Groves

In considering the subject of this presentation–the psychological assessment of the deaf-blind child–I was reminded of the children's story by Leo Lionni called *Inch by Inch*. In this story the protagonist is the inchworm. This busy little creature stretches and shrinks over and around all of nature's wonders. Each leaf, stone, flower, and grain of sand is measured relentlessly. The inchworm knows the object only in terms of its length, its width, and its height. He misses the nuances of the thing measured–the unique color of the flower and the way it tilts toward the sun, the network of veins in the leaf and its rather perfect symmetry, and the texture and striations of the stone. The inchworm is so involved in methodically measuring that he fails to see the other qualities and characteristics that are interrelated attributes of the object.

In the assessment of the deaf-blind child we want to expand the modus operandi of the inchworm. We must go beyond the segmented measurement of the child's systems: how much he hears, sees, tastes, touches, flicks, bangs his head, pulls to sit, chews, and uses his sign or signal for drink. Our task in the psychological assessment of the child is to view, and to report how the child uses, his strengths and weaknesses to receive information about his world.

We must be equally concerned with how the child may defend against this reception of information. Further, we need to attend carefully to the manner in which the child organizes this received sensory data or information into an understanding of his world. Finally, our focus must be on the study of how the child expresses or acts out the "world view" he has constructed about people and objects and their relations.

Children are quite adept in forcing the world to conform to their available levels of action and understanding. So, too, is the deaf-blind child. However, we are confused by or unappreciative of the deaf-blind child's devised ways of understanding the world. Hence, we proceed to modify the child's ways of expressing understanding. We change these expressions into mannerisms that conform to our ways of making sense of the world around us. We have so much to learn from deaf-blind children in observing how they fit people and objects into their available repertoire of skills or action patterns. Hold your breath, restrain your hands, and watch, listen, and take time to observe these ways before extinguishing, modifying, or shaping the behavior into something else. Study and speculate on these behaviors in terms of their possible meaning for the child. It is truly a chance for us to gain some entry into the child's own world and, possibly, to understand the way in which the child understands.

Tools of Assessment

Observational skills that are rooted in a solid sense of the sequential and qualitative nature of development are, in my mind, the primary tools of psychological assessment. Through the exercise of these skills, we come to put together a tentative picture of the child's world, person, and object view. It is through use of the integrative function of developmental observation that we avoid segmenting the child into separate functioning systems and into logs and profiles of the child's separate systems, filled with a series of pluses and minuses, passes and failures. Our question must always be: How does the child get these pluses and those minuses, and how do they work for and against the child in constructing some frameworks for understanding the multitude and variety of surrounding stimuli?

Many kits, test batteries, and evaluation scales are extremely helpful in this process. The danger in their use is that we may surrender our observational skills to the instruments; we may reify the score, criterion measure, or milestone accomplishment. The consequence of this is that we have "inchwormed" the child and neglected his or her unique system of organization and the way it is used to react and respond to the world. In the appendix to this paper, I have listed several

assessment instruments which have been found to be helpful in evaluating the deaf-blind child.

Case History

I would like to discuss an observational session in the psychological assessment of a deaf-blind child. I hope that this case will illustrate the rich data one can gain about the child's cognitive structures and functioning through observation of and interaction with the child.

"T" is a seven-year-old female who has been diagnosed as deaf-blind. She has no movement in her legs and spends most of her time in a wheelchair. T was observed to engage in the following behavior sequence: With the back of her right hand, she would rub against her mouth, then very rapidly move to contact her right ear with the back of her right hand. She then moved this same hand to a contact position with the top of her head. Once this sequence of behavior was completed, she would repeat it.

What data have we gained at this point in our observation?

Observation I.

T uses the back of her hand for contact with objects (mouth, ears, and top of head). With the hand in this position, there is little opportunity for grasping and exploratory manipulation of these "objects" she is contacting.

Speculations and hypotheses to be considered:

1. The palm and fingers of T's hand may be extraordinarily sensitive to tactual stimulation, so much so that she may need to defend against the use of the palms and fingers as sensory receptors.
2. The reverse is also possible. The palms and fingers of T's hand may be hypersensitive to tactual input.
3. T's flexed hand position and her lack of wrist rotation as she contacts her mouth, ears, and head may be a function of her motor impairment.
4. There may be a combination of all of the above.

Observation II.

In her contact pattern the back of her right hand was limited to touching only the right side of her face.

Speculations and hypotheses to be considered:

1. Lack of integration and internal awareness of sides of body is demonstrated through the restriction of the right hand to the right side of the face, not crossing the midline to the left side of the face.

As we generate speculations and hypotheses, we can develop possible intervention or remedial approaches that may provide added information about the child and the solidness of the ideas or hypotheses we have formed about the child and her behavior. For example, from the above observation we might try (a) to work on simultaneous engagement of arms and hands in a symmetrical exploration of center and sides of the head and face; (b) to work on engagement of two hands together at midline at the mouth; or (c) to get a physical therapy consultation and request specific exercises for arm extension, wrist rotation, and grasping.

Observation III.

We next entered into this sequence of behaviors that T had devised by placing a loose cloth hat on T's head. She at first demonstrated no awareness of the "chapeau." She began her ritual once more; however, upon initiating the third step of the sequence, she paused, registered a look of surprise, and commenced to rub her covered hair with the back of her hand.

Speculations and hypotheses to be considered:

1. T showed awareness of the novel stimuli provided by the hat.
2. She exhibited lack of motor ability to change this imposed situation. T could not or did not rotate her wrist in order to allow for the fingers to grasp at the cloth and remove it.
3. There was registration of sufficient stimuli from the cloth hat to maintain T's exploration with the back of her hand for a 30-second period.
4. T was able to inhibit the renewal of the behavior sequence for exploration of the novel stimulus.
5. T, by her reaction, showed that she could discriminate at a very basic level the difference she felt between hair and cloth.

Observation IV

We next removed the cloth "hat" from T's head and placed it over and around her right hand. The observations of T in this predicament were fascinating to us. She looked shocked and then somewhat resigned. For the first time she made eye contact with us. This gave us the impression that she may have attributed to us the action which changed her normal situation. This is an important type of awareness. T seemed to surrender to her fate. She was resigned and sat passively slumped in her wheelchair.

At this juncture in the observation of T, we were struck by the following possibilities:

T's hand was like an object to her, not an integrated and known part of her body. We pictured in our mind the four-month-old infant who grasps an object when it, as well as the hand, are within the child's visual field. The infant then

fervently mouths the object, bangs and shakes it to its side, and perhaps scrapes it against the side of the crib, then repeats this magnificent repertoire of actions. The infant knows the object as a graspable, mouthable, and shakable object. If the object grasped does not conform to this way of "knowing," the infant does not "believe" the object to be an object at all. Additionally, if the object being grasped, mouthed, and scraped is covered or falls from sight or contact, the infant considers the object nonexistent. "Out of sight; out of mind" describes the infant's understanding of the world at this stage of development. In effect, the infant might be saying to objects: "You must conform to my action patterns if I am to recognize and value you as an object."

Think of T as using her hand as an object. She used it first for mouthing, then for sliding and pressing against the ear, and then for placing it on her head for a different way of "knowing" this object we call the hand. This is the way T had come to "know" the object hand. Granted, this is primitive knowledge. But it needs to be seen as a way of knowing before it is discounted as a self-stimulating and ritualistic behavior to be extinguished.

This is T's base of operation, and we need to be in on it to appropriately assess and plan for a developmentally relevant program for her. We need to understand how the child "knows," in order to help broaden the ways of knowing. We do not accomplish this by taking the child's "knowing" behaviors away.

Implications

Now let's go back to T, sitting resigned to the fate that her hand, known through its action patterns on her mouth, ear, and head, is gone. The feedback T received from her hand under the cover was not sufficient to notify her that her hand still existed under the cover. Her hand-object did not conform to her ways of knowing it. Hence, it did not exist. It is as though at T's stage of development, the object and the action on the object are one. The implications of these observations for planning interventions might be that T seems to know one object (hand) through three object-action sequences (contact hand-mouth, hand-ear, hand-top of head).

Two goals are suggested:

1. To expand the *number* and *type* of objects known through these action patterns. The first object to be "known" in this manner might be the palm and fingers of T's hand. A graspable object might then be introduced for exploration in this sequence.

2. To expand the repertoire of object-action patterns by actions such as banging the hand or a bean bag on a metal surface or in water, ensuring that the object and hand are both within the visual field.

Conclusion

The last part of the observation to be shared during the presentation follows:

Observation V

We left T sitting in her wheelchair. Now we tried to help T extend the hand that was flexed to her side to approach the covered hand. She began to finger the cover, to scratch at the cover with her index finger, and then jerkily to shake the cover. She still did not seem to know that the treasured right hand was underneath the cover.

Crucial data was gathered in this observation. It seemed as though T could act on the object (cloth) when, *and only when,* that object and that hand were in the same visual field. When the action was separated from the object, neither the hand nor the cloth really existed. Once the arm and hand were in the same visual field, T began the action-object patterns described above. These pullings and scratchings of the cloth were beginning to be visually guided.

We could have dismissed T's lack of action-object patterns as being a result of her motor dysfunction, of her ritualistic behavior, or of a lack of motivation—all of which may have played a role in T's developmental status but none of which explained how T organized her knowledge of the object.

T began to spend some time each day on a "prone board" or a "wedge," which was positioned on the floor. Being in this position helped her to extend her arms and hands and hence helped her see them act on objects. She began to coordinate her ways of knowing objects with her vision. T was gaining experience which allowed her to know objects in a variety of different ways. She would bang, roll, and drop objects. When the object rolled from view, T began to look after the object. Through her increased repertoire of action-object patterns, T began to "etch" knowledge packets or images of objects in her mind. This kind of "etching" is crucial to the child's further cognitive development. The material for this etching comes through the sensory-motor knowing of the object.

I have been redundant in stating the importance of combining long-term observation with test batteries, evaluation scales, and assessment kits. It is as though these instruments help keep us developmentally grounded, sequenced, and focused on specific areas of performance. Our observational skills help us interpret and speculate on the unique nature of the child's system and the varying qualities of the child's responses.

Assessment Instruments

Intelligence

The Bayley Scales of Infant Development. Consists of mental and motor scales and an infant behavior record for assessing development of children from two months to thirty months.

Catell Infant Intelligence Scale. Milestone-like ratings giving mental age and IQ ages from two months to four years.

Columbia Mental Maturity Scale. Nonverbal test, maturity index. Ages three and a half to nine-plus years.

Denver Developmental Screening Test. Screening device only: gross motor, fine motor, adaptive, language, and personal-social functioning. Ages birth through six years.

Gesell Developmental Schedules. Milestone-like scores in motor, adaptive, language, and personal-social and key ages. Gives a developmental quotient for ages one month through six years.

McCarthy Scales of Children's Abilities. General cognitive based on verbal, perceptual-performance, and quantitative scales. Memory and motor scales plus hand-eye laterality section.

Merrill-Palmer Scale of Mental Tests. Eighteen months through six years.

Raven Progressive Matrices. Nonverbal, grade-level score which is convertible into intellectual capacity level. Ages five to eleven years.

Stanford-Binet Scale, Form L-M. Mental age and IQ. Ages from two years through adult.

Wechsler Adult Intelligence Test (WAIS).

Wechsler Intelligence Scale for Children (WISC).

Wechsler Preschool and Primary Scale of Intelligence (WIPPSI). Verbal and performance score/IQ and full-scale score and IQ. Ages four through six and a half years.

Aptitude Development and Achievement Evaluation Scales

Callier-Azusa Scale. Particularly designed for the assessment and evaluation of deaf-blind, multihandicapped children. Quite extensive, with examples of types of behaviors. Teacher can chart a profile of a child and can compare the child to himself or herself. Quite useful.

Koontz Child Developmental Scale Program: Training Activities for the First 48 Months. Good for developmental level and possible remedial activities.

Psychoeducational Evaluation of the Preschool Child: A Manual Utilizing the Haeussermann Approach. Good probes; ages variable.

Tests for the Hearing Impaired:

Leiter International Performance Scale

Tests for the Visually Impaired and Blind:

Hayes-Binet Intelligence Test for the Blind

Maxfield-Buckholz Scale (for preschool blind children)

Visual Efficiency Screening Test or Kit: Natalie Barrega. Good sequent and remedial plans.

Visual Assessment and Training of the Deaf-Blind Child

Presented by Ruth Seth Funderburg
Assistant Professor, Department of Special Education, University of Hawaii at Manoa

Though we sometimes fragment our learning about the child, it is pertinent to mention that we are talking about the total child, the whole child. As clinical teachers or special education teachers, we should always be teaching clinically. One really cannot separate assessment from the teaching role. We are constantly learning from the children as they show us new ways to assess. As the deaf-blind child is being evaluated, as he or she spins the shiny bottles, the child is using vision, which allows a teacher to assess the child's visual behaviors. In this situation the child is working motorically, communicating through his or her own form of language, and demonstrating cognition. Vision is the sensory area which I will emphasize; however, the use of vision is integrated with language, hearing, motor development, cognition, and socialization.

Professionals such as psychologists have to stay within the realm of standardized scores. We as teachers have no such constraints. From exposure to the children, we can learn new ways of assessing and documenting behaviors which the standardized tests, limited to curren' terminology or standardized scores, might not show us. We as teachers must not restrict ourselves. We can also learn from the many professionals who work with our teams, because they bring a wide range of competencies to complement our diagnostic teaching.

The psychological interventions described are really probing the same skills used in clinical teaching and assessment. We need input from these professionals. One of the most fascinating challenges about educating these handicapped children is that they have a multiplicity of handicaps and need a multiplicity of people working for them and with them. I think, then, we are the most favored of people because we do not have to stay in our own little niche; we can incorporate all kinds of information in future planning.

The child is our best teacher. We can learn best by observing the child demonstrating behavioral needs, by pointing the way. Whatever we do we should keep the individual child as the focus of training or assessment. Training and assessment should be going on simultaneously as part of the clinical teaching cycle.

The role of vision and visual learning is intrinsically related to the sighted child's learning—perceptual, motoric, cognitive, social, and emotional. Piaget, Gessell, and others who have worked with early child and infant development point out that vision is one of the primary senses that enables the child to develop and move out from his or her inner sphere to an outer sphere in concentric circles—out into the world, the environment. We must also remember that a blind child or a deaf-blind child is a child, first. We must be aware of the literature and studies of normal child and infant development in order to determine the skills and stimuli needed in the sequential development, training, and assessment of the deaf-blind multihandicapped child.

Necessity of Training

In the 1920s and 1930s, children who were visually impaired were educated in "sight saving" or "sight conservation" classes. It was the belief of educators of this period that the child of limited vision needed to "save" or "conserve" what little vision he had so as not to damage the remaining vision. In recent years eye specialists have discovered that the opposite is true. In order to help the child learn in a more meaningful manner, we must train that vision. Visual training of low-vision children, including deaf-blind children, has been encouraged. This training neither damages nor destroys any residual vision. To the contrary, it has been determined that visual training in addition to use of optical aids must be a major goal of any training program for the deaf-blind child. However, the actual type of functional use will depend on the amount and character of the remaining vision.

Visual training was supported by Natalie Barrega's doctoral dissertation (Barrega, 1964). She is the mother of a visually handicapped child as well

as an educator. She felt that visually impaired children with extremely low degrees of remaining vision would profit from specialized visual training which made use of appropriate materials, and she presented evidence that through training and visual stimulation, the subjects' visual efficiency did increase. As an adjunct to that, it also improved their behavior psychologically–a reference to the total child.

Systematic training of residual vision is a must in programs for deaf-blind children. It aids the educator not only in assessing visual functioning, but also in developing and implementing educational tasks for the child. For the child himself, it offers increased visual potential and is an important link in the subsequent growth of his intellectual and motor development. The role of vision and visual learning is intrinsically connected with a sighted child's learning–motor, cognitive, social, and emotional. It is crucial that the deaf-blind child, whose other major information sense (hearing) is also impaired, be exposed to as many means of learning efficiently as possible.

The low-vision child is primarily the subject of this paper. However, it becomes very difficult even when working with higher functioning children to ascertain and cope with language problems of input and output and to communicate to them the evaluative task.

Terminology Used In Visual Functioning

So many terms are bandied about that pertain to visual functioning that at least the major ones should be defined.

1. *Visual Acuity*

Visual acuity is considered a measurable amount of distance vision, or the ability to discriminate objects at specified distances. Visual acuity is most popularly and commonly measured by the use of the Snellen Chart and is expressed in the form of a fraction–i.e., 20/70, 20/200. For reasons that are apparent, visual acuity cannot be measured by the Snellen Chart for the majority of deaf-blind children. The Snellen Chart can be used for high functioning children.

2. *Visual Sensation*

According to Efron (1975), visual sensation refers to the reception of light or form by the retina and later the reception of the image by the brain. Visual acuity is just a measurable aspect of sensation.

3. *Visual Perception*

Visual perception is thought of as the capacity to interpret or give meaning to what is seen (the visual sensations). It may also be described in visual terms of discrimination and recognition of qualities and relationships. Visual perception requires the integrity of the central nervous system.

4. *Visual-Motor Development*

Visual-motor development is an integrated relationship between vision and movement or action. The brain directs and focuses visual abilities with other sensory and motor abilities in other parts of the body. Examples are eye-hand and eye-foot coordination.

5. *Visual Efficiency*

Visual efficiency refers to the competency of the visual mechanism (the eye) and to the extent it receives and processes information. Visual efficiency of the deaf-blind child is difficult to understand, particularly since the child usually demonstrates nonverbal behaviors, and so much sensory information is unavailable to him. Therefore, we have to look at visual efficiency as an individual thing.

The implications are that visual functioning for the deaf-blind must be developed by training. It is felt that the peripheral vision does not in itself improve with training. On the other hand, the central processes involved become more functional as they are trained through controlled intervention (Chalfant and Scheffelin, 1969; Roberts, 1972).

Evaluation of Visual Functioning

Two major sources of information are useful concerning the visual functioning of the deaf-blind child. The first is the periodic evaluation by an eye specialist, which describes the type and extent of visual impairment and the related health problems or diseases. This medical or optometric evaluation usually takes place in a clinic or office. The visual acuity of the blind child formerly determined school entrance.

Now we are more interested in visual functioning, which brings us to the second kind of evaluation, the educational evaluation or assessment. The educational assessment should be an ongoing assessment performed by the teachers, aides, and parents. This type of assessment describes the child's functional vision as it is used in everyday activities and in familiar settings. The teacher uses information received from the ophthalmologist, optometrist, psychologist, and

parents along with educational observations to prepare subsequent prescriptions or training programs for the individual deaf-blind child (Roberts, 1974). Thus, if good records are kept, long- and short-term goals can be constantly adapted and evaluated through the interpretation of this information.

The role of the teacher is most important. He or she is the "constant" who establishes the rapport so necessary for stimulating the child's trust and motivation. The teacher sees the child on a day-to-day basis in the learning environment which is most familiar and "comfortable" to the child. It is the teacher's responsibility to understand the developmental scales of normal children in order to present visual stimuli in a sequential fashion. Some developmental scales such as the Callier-Azusa Scales and Efron and DuBoff's Visual Developmental Scales (1975) have been compiled or adapted from normal scales especially for their work with deaf-blind children.

In order to assess functional levels of behavior, at least three categories should be used by the teacher: (1) the educational assessment of children; (2) the analysis of learning tasks; and (3) controlled intervention. References to controlled intervention point out the necessity of detail in planning and establishing criteria for observation and time scheduling.

Assessment can go on in many situations, under many conditions. The important thing is to observe behaviors while they are going on, not just the results of those behaviors. It is also most important to note the situation and when these behaviors occurred. The child's use of vision can be observed (1) in free play; (2) in travel vision or mobility; (3) in reaction to and performance of environmental tasks; (4) in the analysis of tasks that the child seems to be motivated to initiate; (5) in response to light, color, or absence of color and differences in size and shape of objects; (6) in the child's reaction to familiar and unfamiliar objects and people; and (7) in the child's reaction to movement stimuli (to the side, in front).

Different tasks call for different functioning levels, and the type of tasks set up to analyze or assess vision depends upon the functioning level of the child. A high-level child has already gone through a repertoire of skills that have to be introduced sequentially to the low-level child. Efron and DuBoff's *Vision Guide for Teachers of Deaf-Blind Children* (1975) lists three major areas of evaluation: sensation, visual motor, and visual perception. This guide also enables the teacher to see which skills need to be programmed. An important point to note here is that input from the parents to the teacher as to how the child uses his vision and reacts to visual stimuli in the home should also be incorporated into the assessment records of the child. Observations can be recorded in teachers' notebooks, in parents' diaries, and periodically on videotape and film. These recorded observations are also good for nonbiased comparisons of before-and-after behaviors.

Problems in Assessment

Some of the problems in assessment confronting the teacher have been summarized by Roberts (1974):

1. Teachers and other personnel may not have developed skills as observers of child behavior. Teacher education institutions are remiss in training. Observation has to have structure. The key is to watch behaviors and circumstances.

2. Educators have been trained to focus on outcomes of experiences (products) rather than the ways a child learns or uses senses (process). Consistency of response and ways to elicit the response are important.

3. Parents and teachers talk about skills and behaviors in general terms rather than including the conditions under which these behaviors or tasks were demonstrated. What does the child do at home that he or she does not do at school? What are the rewards offered in both places? How about medication?

4. Early diagnosis of visual problems in infants often leads to erroneous assumptions that there is little usable vision, and thus little or no stimulation is thought necessary. With the severely multihandicapped, stimulation is a problem. A child's low tolerance for stimulation is another factor. Labeling is circular. As a result the teacher does not expect a child to achieve beyond his or her capacity, and consequently the child is not challenged and stimulated to do so. Teacher expectancies do appear to influence pupil progress.

5. For most kinds of evaluation of performance, we tend to rely on auditory stimuli and responses. The deaf-blind child might not be able to receive auditory stimuli or to give a verbal response. Often a disparity exists between verbal responses and basic understanding of concepts. We need to be building language and language concepts through whatever means are available.

6. Educational records by nature are lengthy in comparison to medical records or acuity measurements. Educational records then become massive in contrast and discourage notetaking. Too long have we as educators looked to the medical model. Some of the shortcuts to notetaking have been noted (e.g., television).

7. The greatest deterrent to systematic assessment of visual functioning is the difficulty of isolating purely visual activity from the effects of cognitive, psycho-social, or other sensory functions. It takes time and insight to separate the task input from the mode or method of response.

8. Visual behaviors may change with experience and sensory training. Because effective assessment of visual function is continuous, we need effective ways to record these changes for easy use and interpretation. The members of the team working with the children need ways of communicating less through professional jargon and more through concise language.

Visual Training

Vision is considered a voluntary sense; that is, it must be directed by the child—as opposed to listening, smelling, and feeling, in which the sensations can be received even when one is not paying attention to the stimuli. Visual perception is a learned ability; that is, one can give meaning to the visual sensation. The child's wanting to see or the motivation to use vision is another element in vision training. Teachers must encourage the development of vision beyond the sensation stage, even though many of these children have been passive. Because of erroneous assumptions many educators have neglected sensory stimulation and visual efficiency. One cannot teach visual acuity, but visual skills can be learned. Many educators and psychologists also feel that visual training should have a motor component; reference is made to the work of Piaget and Gesell. Handicapped children must go through the same sequential steps of visual skills as sighted children; however, we must emphasize that there will be a developmental lag.

In training, the teacher's main job is to get the child to attend visually. The child must be shown how to attend and what to attend to, for there are many types of remaining sight possible—e.g., restricted field vision, such as tunnel vision or peripheral vision; light perception; scanning vision; and gross form perception. Individual functioning determines the ability to improve visual functioning, but teacher attitudes and expectations can also affect the visual efficiency of these children as well.

Training Pointers

Vision training progresses through stages of awareness of the stimuli, tolerance of the stimuli, recognition of the stimuli, interpretation of the stimuli, and application of meaning of the stimuli. There is no clear-cut boundary between visual acuity and the processing of visual stimuli. There appears instead to be a continuum of tasks (Chalfant and Scheffelin, 1969).

The visual motor tasks include two main classes: (1) the ocular-motor tasks, which are responsible for the reception of the visual stimulus; and (2) cognitive tasks, which require the analysis and synthesis of visual information.

In general, visual processing tasks to aid in visual training would then be distinguishing light from no light, achieving binocular fusion, achieving convergence, scanning, eye coordinating, determining spatial relationships, gross and fine visual discriminations, and object recognition.

In training for visual functioning and efficiency, the teacher is reminded of the stages which are mentioned above, through which vision progresses. In order for the training to be meaningful, one must stress the importance of how the ocular motor tasks affect visual processing of information in respect to cognitive tasks. Whereas cognition involves awareness and judgment, the sequential nature of the training hierarchy must also be emphasized.

Since assessment of visual functioning was described in terms of sensation, visual-motor and visual perception training will be described under the same headings.

1. *Sensation*

Sensation is primary and is related to attending. Sensation can be stimulated through light perception; that is, through the ability to recognize the presence or absence of light in response to the use of such sources as penlight, candles, colored lights, Christmas lights, shiny objects, and reflected lights. Many rubella children show abnormal reaction to light, such as "light gazing" or self-stimulation. This response should be channeled in positive ways and light used as a reward. Flashing lights may not be tolerated by some children, so one should use caution.

Gross form perception includes near-object acuity and distant-object acuity. In near vision, size, shape, and color are important, and in distant

vision one is refining skills that lead to the manipulation of objects.

2. *Visual Motor Response*

The purpose of visual-motor training is to develop the skills essential for visual perception. activities fall under the perceptual-motor domain, entailing a motor response to vision such as scanning (zig-zag scanning, pursuit of a moving object, and learned systematic scanning), focusing on a moving object, and judging distance and eye coordination with other parts of the body. Getting and maintaining eye contact is also an important skill for deaf-blind children.

The lower functioning child will have to be given tasks to develop these skills, whereas middle functioning and higher functioning children will have progressed from minimal motor control activities to those cognitive tasks requiring eye-hand and eye-foot coordination, such as learning readiness tasks. Body awareness is an important variable at all levels.

3. *Visual Perception*

This third area, visual perception, is tied into cognitive skills and requires central nervous system integrity in order for the child to get as much meaning from the stimulus as possible. (Body orientation and spatial awareness, discrimination tasks of differing complexities, and object recognition are three major categories of visual perception.) Visual discrimination tasks range from gross matching at the lower levels to finer and more difficult discriminations at the higher levels. Speed of perception, duration of presentation, object number, color, shape, contrast and size, and directionality are major components of visual perception. Lower and middle functioning children will be generally less skilled in this area.

Implications and Summary

As we progressed from the days of "sight saving" techniques and moved into the realm of visual training, we came to realize the value of evaluating and training the child to levels that were previously not thought possible. We must be cautious that we do not stress the dearth of vision to the point where we omit vision and intersensory integration of the whole child. When we first started working with rubella epidemic children, we used untrained staff and untried methods in some circumstances that proved "necessity *was* the mother of invention." We found or created tools that have proved useful in subsequent years for training and evaluating deaf-blind multihandicapped children. As we promote the visual efficiency of our deaf-blind children, may we also promote the visual efficiency of their teachers. We need new and better ways of observing visual behaviors. We need to learn to share some of the reliable assessment tools and remedial techniques that have been proven in longitudinal approaches with our specific population—deaf-blind children.

We have come a long way from the sight saving days, but more educational and psychological research is needed to make our work as teachers more efficient.

Bibliography

1. Robbins, Nan. *Educational Beginnings with Deaf-Blind Children.* Perkins Publication No. 21. Watertown, Mass.: Perkins School for the Blind, 1964.
2. Robbins, Nan, and Gertrude Stenquist. *The Deaf-Blind "Rubella" Child.* Perkins Publication No. 25. Watertown Mass.: Perkins School for the Blind, January, 1967.
3. Efron, Marvin, "Hints for Examining and Reporting the Vision of Deaf-Blind Children," 1975 (unpublished paper). Efron, Marvin, and Beth Reilly DuBoff. *A Vision Guide for Teachers of Deaf-Blind Children. North Carolina Department of Public Instruction.* Winston Salem, N.C.: Special Education Instructional Materials Development Center, 1975.
4. Barrega, Natalie. *Increased Visual Behavior in Low Vision Children.* New York: American Foundation for the Blind, 1967.
5. Roberts, Ferne Root. *"The Educator's Assessment of Visual Functioning,"* in *Proceedings of the National Symposium for the Deaf-Blind,* July 7–10, 1972, Asilomar, Pacific Grove,

Calif. Sacramento, Calif.: California State Department of Education, 1974.
6. Buktenica, Norman A. *Visual Learning.* San Rafael, Calif.: Dimensions Publishing Co., 1968.
7. Gesell, Arnold L., F. Ilg, and G. Bullis. *Vision: Its Development in Infant and Child.* New York: Harper and Row, 1950.
8. Barrega, Natalie. "Teaching Children with Low Vision," *The New Outlook* (December, 1964).
9. Roberts, Ferne Root. "Visual Evaluations of Deaf-Blind Children," in *Innovative and Experimental Happenings in Deaf-Blind Education.* Proceedings from the First Annual Spring Workshop for Professionals Serving Deaf-Blind Children in the Mid-Atlantic Region (South), 1974, Wrightsville Beach, N.C. Raleigh, N.C.: State Department of Public Instruction. [n.d.]
10. Efron, Marvin. "Classroom Techniques for the Evaluation of Functional Vision," in *Innovative and Experimental Happenings in Deaf-Blind Education.* Proceedings from the First Annual Spring Workshop for Professionals Serving Deaf-Blind Children in the Mid-Atlantic Region (South), 1974, Wrightsville Beach, N.C. Raleigh, N.C.: State Department of Public Instruction. [n.d.]
11. Chalfant, James C., and Margaret Scheffelin. *Central Processing Dysfunctions in Children: A Review of the Research.* Bethesda, Md.: U.S. Department of Health, Education, and Welfare, 1969.

Auditory Evaluation of the Deaf-Blind and Multihandicapped Child: Implications for Training

Presented by Barbara Franklin, Ph.D.
Clinical Audiologist; Coordinator, Deaf-Blind Program, Department of Special Education, San Francisco State University

The idea of "diagnostic teaching"—diagnosing the child as you teach the child—was developed by Mildred McGinnis many years ago at the Central Institute for the Deaf in St. Louis, Missouri. One learns a lot about a child by teaching. This information helps in the diagnosis, and as the diagnosis becomes clearer, it, in turn, helps one to teach the child better. This philosophy seems particularly appropriate for the children we are considering at this conference. I believe that diagnosis and teaching are inseparable.

The auditory stimuli appropriate for testing the hearing of children are also appropriate for auditory training in the classroom. The responses that can be expected during the hearing testing can also be expected during auditory training in the classroom. In other words, the material I am about to present can be applied to the evaluation of hearing by the audiologist as well as to the training of hearing by the classroom teacher.

Most children under four years of age and children of all ages that are severely impaired, multihandicapped, and deaf-blind find pure tones meaningless. However, these children will often respond to more conventional auditory stimuli such as sound toys, environmental sounds, and speech. It may be that these sounds have acquired meaning for the children. Some of the more effective sound toys are cowbells, squeeze toys, shakers such as beans in a can, and rattles.

The Ewings (1944) found that the common household sounds that got the most response from infants included bottles clinking and a spoon tinkling in a cup (both of which signify food) and the click of a door handle. Each of you will have to determine the most appropriate sounds for your children, depending upon the particular environment in which you live.

However, the most effective auditory stimuli of all is the easiest to use, since it is the human voice, which is always available. In addition, an infant will usually respond best to its own mother's voice.

Responses by Age Level

I will now describe the responses to be expected at each age level. If you know the kind of response the child should be making at a particular age and the child makes a different response, you can use the hearing test as a test of general motor development. Remember, the testing and auditory training should always be done with sound toys, environmental sounds, and speech.

From birth to six weeks, the response to sound includes arousal from sleep. Other responses of the newborn include:

1. Reflexive—moro response (stiffening of the extremities) and eye blink.
2. Change in ongoing behavior. Activity either increases or decreases. For example, if the baby is crying and stops upon hearing the sound, that is a response. And if the baby is quiet and starts to cry upon hearing the sound, that is also a response.

From six weeks to four months, the infant's responses to the auditory stimuli are essentially the same as at the birth-to-six-week age level except for a rudimentary head turn, which is an orienting response that is a searching for sound.

The response to sound at four to seven months is a 90-degree head turn to either side, the first sign of the ability to localize.

The response to sound at seven to nine months is localizing to the side and then indirectly down. In order to get this response, one can seat the child in the mother's lap and present the sound out of sight, to one side of the chair, near the floor, and then to the other side. If the child responds with just a head turn to the side instead of to the side and down, this may indicate that the sound has been heard but the type of head turn may indicate a lowered developmental level. Instead of using the response of a seven-to-nine month old, the response is that of an infant four to seven months old.

The response of the infant of nine to thirteen months of age is directly down. The infant at this

stage can locate sound directly below. Again, if the child responds by just a head turn to one side or to the side and then down, motor retardation may be indicated.

Before the age of seven months, babbling sounds such as "buh buh buh" can be used. After this age some recommended speech stimuli are "bye bye," the child's name, "no no," and "oh oh." Verbal commands can also be used by the second year, such as "sit down," "stand up," and "wash your hands."

The responses of the child from thirteen to sixteen months of age is to the side and up. If the child is unable to locate a sound over his head by this age, again a delay in motor development may be indicated.

The response of the child from sixteen to twenty-one months of age is directly above.

Between twenty-one and twenty-four months of age, the child is able to localize and find sound at any angle.

Alternative Techniques

Alternative techniques can be used in order to obtain audiological information for those children who cannot be tested by conventional procedures. A variety of auditory stimuli—speech, music, a trumpet playing simple nursery rhymes, and sound toys—can be recorded. The tape is played through an audiometer, and the intensity can be regulated by the attenuator. The speech, music, and trumpet are used to determine awareness thresholds and in some instances the ability to discriminate different auditory stimuli. The sound toys are used to obtain a crude audiogram, since the frequency range of the toys was established through spectrographic analysis. For example, there is a bell with no visible energy below 1,500 Hz. and another bell with no visible energy below 2,500 Hz. If a child responds to one or both of these bells, a crude audiogram can be obtained.

Audiological Evaluation

Subject: G.T., Five Years Old

Audiologist's observations:

3/13/73 – Detection thresholds of 90 db. right and left ear, fairly consistent

5/24/73 – Detection thresholds of 80 db., right and left ear. Rocked to music; different responses than to trumpet. Reached for right and left earphone consistently when stimuli was changed from ear to ear.

General observations of improvement in auditory responses when wearing hearing aids:

1. Increased consistency of responses
2. Increased awareness of differences among auditory stimuli
3. Improved threshold of detection of auditory stimuli

Teacher's observations:

10/26/72 – G.T. is wearing a Brand X binaural hearing aid, which is on loan from Barbara Franklin, Clinical Audiologist, both at home and at school.

10/27/72 – G.T. is making many new and different sounds at school and babbles almost continuously.

2/9/73 – Sounds made most often by G.T.: "yuh-geh," "O" (interrupted), "gu," "hu," and "ay."

5/4/73 – Believe that G.T. hears the music on the stereo. She loves being thrown in the air, jumping, bouncing to the music. It seems that she moves to the music even when 25 feet away. The first time she swayed during coactive movement was in time to the music at the other end of the room.

6/7/73 – G.T. is now watching mouth and tongue movements!

Mother's observations:

10/27/72 – "Thanks so much for the new hearing aids G.T. is now using. I think it helps her a lot to hear. When she reached home she was very happy and was trying to say some sort of words because she could hear her own voice. I talked to her as if she could hear me clearly and she laughed every time I said something to her."

Audiologist's recommendations:

G.T.'s consistent responses to sounds over 80 db. would warrant continued use of binaural hearing aids. Since her responses have improved while wearing the Brand X hearing aid, I would recommend this particular hearing aid for G.T.

Audiological Evaluation

Subject: Y.H., Nine Years Old

Audiologist's observations:

4/15/75 – Y.H. was seen by this audiologist for an audiological evaluation. A detection threshold for speech, sound toys (particularly the shaker), and music was obtained at 80 db. for both the

right and left ear. There was a better response when the stimuli were presented to both ears at the same time (bilaterally). Y.H. was more comfortable in the listening situation when the intensity was increased to 90 db. He gave better responses to speech than to the sound toys and music, which indicates some ability to discriminate among different types of auditory stimuli. He fussed when the earphones were first put on, but when he began to be aware of the sound, he didn't want to stop. He maintained his attentive listening for approximately 35 minutes.

4/29/75 – Y.H. was tested with one hearing aid (Brand Y). His other mold was lost. With the hearing aid in his left ear, he listened attentively with his head next to the speaker, with the intensity as low as 45 db. Again he preferred speech and got excited every time the tape played the voice segments. He vocalized several times with the speech. He sat and listened attentively for 30 minutes. When the speaker was turned off, he got up and walked away. When he was about 12 feet away, and the speaker was turned back on at 80 db., he returned to the speaker to listen. This was repeated several times.

Teacher's observations:

The following observations were made in a report in March, 1975:

1. Y.H. has been wearing a Brand Y binaural hearing aid since September, 1973. Before that he wore over-the-ear aids, which were a constant problem due to his hyperactivity.
2. He becomes upset if his hearing aid is taken away. Also, when his batteries run down, he is apt to remove his ear molds.
3. If an ear mold should loosen, he will stop his activity and seek out an adult to replace it.
4. Y.H. will seek out his favorite music box when it is turned on. When the music stops, he puts the box down.
5. In an empty room he will turn if called and locate where the sound comes from.
6. It appears that he is beginning to respond via the ear to "no."

Audiologist's recommendations:

It is recommended that Y.H. be fitted with two body-type hearing aids, of moderate gain and output. Although he has been wearing Brand Y aids, the service on these aids has not been satisfactory. Several of the children who have been wearing a comparable aid–Brand X–have had very good service from this aid and from this company.

Therefore, it is this audiologist's recommendation that Y.H. be fitted with two Brand X hearing aids. (Specific receiver, gain, and output recommendations follow.)

Bibliography

Ewing, I. R., and A. W. G. Ewing. "The Ascertainment of Deafness in Infancy," *Journal of Laryngology and Otolaryngology*, Vol. 59 (1944), 309–333.

Murphy, K. P., and C. M. Smyth. "Responses of Fetus to Auditory Stimulation," *Lancet*, Vol. 1 (1962), 972–973.

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Classroom Management

Presented by Margo Dronek
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A comprehensive management system must be implemented in structuring an individualized program *for* deaf-blind children. Many developed systems are available that may provide a model. While acronyms may vary, the ingredients are basic for controlled accountability and best use of staff. The Child-by-Child Plan adopted in 1973 and presently being revised by the Southwestern Region Deaf-Blind Center is one means of organizing instructional planning for the individual deaf-blind child (Appendix 1).

Program planning includes collecting and recording pertinent data. A team of specialists representing various disciplines can provide necessary information. Parent conferences, past records, developmental tools, and psychological tests are invaluable in ascertaining the developmental level of the child in the basic skill areas. The prioritization of these skill areas should include the recommendations of the multidisciplinary team. Behavioral objectives are then formulated to describe the behavior that you want the child to demonstrate. Objectives should be grouped in the activities of daily living to ensure integration of the whole child.

The next phase is preparing a plan for the organization of instruction. Activities based upon the behavioral objectives are scheduled.

Preplanning is a must in providing a sound, well-structured program. One component of preplanning includes task clarification; a task list for teachers and paraprofessionals clarifies roles and enhances the lines of communication in the classroom (Appendix 2). Decisions are made regarding individual versus group instruction. Strategies are defined.

Lesson plans include the materials and equipment needed, the procedure data regarding anticipated progress, and related activities.

An evaluation component measures the pupil's progress towards goal attainment and instructional effectiveness.

If problem areas appear one might need to analyze the task components as well as the teacher's role in the learning process (Appendix 3). Ascertain the clues the child needs as well as the method for fading the clues out.

Learning centers help the child become oriented to the environment and provide a useful approach in organizing the classroom. Motivation interest centers to develop skills in the basic areas of development are set up. Staff are assigned after the centers are established, since most deaf-blind children will not function independently. To provide the increase in staff ratio, every possible resource must be tapped, including parents, siblings, college students, senior citizens, and peers as tutors. Scheduling students will depend upon each child's functional level; each interest center may not be appropriate for every child. The classroom staff members confer and develop the activities for the centers. Data sheets are kept in each center to record the individual child's performance. Daily progress reports are sent to the parents or ward personnel (a notebook can be used for that purpose).

Organizing and planning for the education of the sensory handicapped student is a complex process. No one method will work for all. Cooperative planning, student grouping, daily schedules, use of space, and recognition and utilization of team talent are critical variables in program planning.

Appendix 1

Southwestern Region Deaf-Blind Center

Deaf-Blind Child: Basic Data

A. Respondent Identification

1. Center's name _____
2. Address _____
3. Name of person completing form _____
4. Telephone number _____

B. Identification of the Deaf-Blind Child

1. Name _____
2. Birthdate _____
3. Parents/guardian address _____
4. School address _____
5. Telephone number _____

C. Personnel Directly or Indirectly Involved with Child

1. Administrator or principal _____
2. Teachers (Include supervisors, teachers, assistant, and student teachers)

_____

_____

3. Aides _____
4. Ancillary staff (Include nurses, occupational and physical therapists, and speech correctionists).

_____

_____

5. Others (Include volunteers, student aides, and so forth.)

_____

_____

Appendix 1: Basic Data (Continued)

D. Child Developmental Plan

1. Developmental assessment tool (s) used _____

2. Date of evaluation _____

Developmental area	Present performance level	Specific objective (s)	Progress report
Example *0.0 EATING*	*Moves food in mouth with tongue*	*When offered semisolid food, child will chew and swallow eight out of ten trials*	*Child still will not chew. Objective modified. When given semisolid food, child will be manipulated through chewing motion and will self-initiate chewing three out of five trials*
Example *0.1 TOILETING*	*When placed on toilet, child will remain seated.*	*When placed on toilet, child will eliminate within 10 minutes 90 percent successfully.*	*Child has achieved objective with a success rate of 50 percent. Will continue working towards 90 percent success.*

NOTE: Not all skill areas may be applicable to each child at the time of evaluation.

Appendix 2

Task List for Teachers and Paraprofessionals[1]

Directions:
In the column to the right of the statement, place the appropriate letter(s) to indicate whether the teacher or paraprofessional/aide should perform the individual tasks (T = teacher; P = paraprofessional, aide).

1. Set up a meeting for home visit		
2. Control pupil problem behaviors and acting out		
3. Observe child's behaviors in the class		
4. Conduct fire drill		
5. Arrange for eye and ear examinations		
6. Set up for lunch time		
7. Write daily progress notes home		
8. Develop activities to meet child's planned objectives		
9. Devise classroom schedule		
10. Change pupils' diapers		
11. Determine necessary methods and materials to attain objectives		
12. Confer with ancillary personnel		
13. Discuss pupil progress in a staff meeting		
14. Discuss/plan summer school program		
15. Prepare pupils to go home		
16. Determine revision for child's stated objectives		
17. Conduct informal evaluation		
18. Evaluate child's progress		
19. Document child's daily progress		
20. Care for class pets		
21. Formulate objectives for pupils		
22. Soothe pupil who is distressed		
23. Feed pupils who need assistance		
24. Work with group of students		
25. Work with individual students		
26. Instruct students in self-help skills		
27. Supervise recess, free time, or playground activities		
28. Instruct volunteers in program rules, in their duties, and in pupil learner objectives		
29. Attend inservice training		
30. Provide or receive instruction in operating new classroom materials/equipment		
31. Secure approval from parents regarding class activities, if necessary		
32. Determine with parent/guardian/ward staff the home objectives for child		
33. Draw up purchase requisitions		
34. Attend program/staff meetings		
35. Recommend/prepare future placement		

[1]Adapted from the Santa Cruz Task Base Composite. Compiled by Audrey C. Single, Administrative Intern, Boston College.

Appendix 3

Task Analysis: Tie-Shoe Removal[1]

Criterion: When given the sign cue "shoe off," learner will remove shoe on six consecutive trials without errors or assistance.

Learner: Joe, ten years old; profoundly deaf; left eye has no vision; right eye has 20/100; moderately retarded.
Entering behavior: Joe can sit on the floor independently, has palmar grasp but no pincer grasp.
Materials: Nonorthopedic tie-shoe.

A. Method

The learner is seated on the floor with legs outstretched. The teacher begins each trial by signing "shoe-off" while facing the child. The teacher is kneeling behind the child throughout the rest of the training session. While seated on the floor, the child will undo the shoe lace of his right foot and will remove the shoe by pulling it off from the heel.

B. Content Task Analysis

1. Locate back of right knee with right hand, palm up.
2. Pull knee up toward chest.
3. Release right hand from back of knee.
4. Locate laces with right hand.
5. Locate end of lace with right hand.
6. Grasp (pincer) end of lace.
7. Pull up lace.
8. Hold lace with right hand.
9. Locate "remainder" of knot with left hand.
10. Insert curled index finger of left hand under "remaining" knot, palm down.
11. Pull up with left hand.
12. Release grasp of right hand.
13. Reach toward top flaps of shoe with both hands.
14. Insert thumbs under flaps, but over tongue of shoe.
15. Push thumbs out to sides of shoe.
16. Remove thumbs from side flaps.
17. Lower right knee toward right, keeping knee bent.
18. Reach toward ankle with right hand.
19. Grasp right ankle with right hand, palm down.
20. Locate heel of shoe with left hand.
21. Place heel of left hand on back of heel of right shoe, finger on bottom of heel.
22. Push shoe away from body with left hand, while pulling ankle with right hand.
23. Release ankle.
24. Locate toe of shoe with right hand.
25. Grasp toe of shoe.
26. Lift shoe with right hand.
27. Place shoe on floor.

C. Process Task Analysis

1. Format

   Each trial will make use of a total task presentation, with the trainer directly manipulating the child's hands through every step of the content.

2. Feedback

   Physical Prompt Hierarchy: a nonverbal, tactile, information system. *Least* information given starts at point one and ranges to *most* information given at point six. The teacher should do the following:

   a. Touch slightly student's manipulating shoulder.
   b. Push gently student's manipulating shoulder.
   c. Touch student's elbow above manipulating shoulder.

[1]Derived from the research of Marc Gold, Institute for Child Behavior and Development, University of Illinois, Champaign-Urbana, Ill. 61820. Compiled by Audrey Single and Ron Lecours, administrative interns, Boston College.

Appendix 3: Tie-Shoe Removal (Continued)

d. Push student's elbow in desired direction.
e. Push student's wrist in desired direction.
f. Place student's hand between teacher's hand and the manipulated item and perform the necessary manipulations.

3. Implementation of the Feedback
   a. Gradually diminish amount of feedback and assistance using the Physical Prompt Hierarchy.
   b. Vary the types of prompts used so as to avoid associating one specific activity with *only* one specific prompt.
   c. Use the following procedures:
      (1) Grasp child's right hand and guide the child's hand to the back of his or her right knee, palm up.
      (2) Pull child's hand toward child, lifting child's knee toward chest.
      (3) Pull child's hand out from under knee.
      (4) Guide child's right hand toward laces on right shoe.
      (5) Direct child's right hand to end of lace.
      (6) Assist child to form pincer grasp around end of lace, with right hand.
      (7) Lift child's hand up while maintaining pincer grasp.

(Continue for each step of the content.)

D. Revisions

When it appears necessary to revise some aspect of the analysis in order to facilitate learning, consider the following:

1. Process Revision:
   What other teaching techniques could be used? Does the learner know what is expected? Is the feedback effective?

2. Content Revision:
   Is the content reduced to enough detail? Are component steps too big? Are steps omitted?

3. Method Revision:
   Is there an alternative method? Would an innovative alternative better suit the learner?

Appendix 3: Tie-Shoe Removal (Continued)

E. Data Collection

Data on the training session can be recorded on a form similar to the one below. Indicate by (+) when the student has, or by (-) when the student has not, completed a particular step of the content analysis without errors or prompts, and give other anecdotal information that might be of interest.

Trial:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Date:	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Content															
1. Locate															
2. Pull															
3. Release															
4. Locate															
5. Locate															
6. Grasp															
7. Pull															
8. Hold															
9. Locate															
10. Insert															
11. Pull															
12. Release															
13. Reach															
14. Insert															
15. Push															
16. Remove															
17. Lower															
18. Reach															

Speech and Language Evaluation of the Deaf-Blind and Multihandicapped Child: Implications for Training

Presented by Barbara Franklin, Ph.D.
Clinical Audiologist; Coordinator, Deaf-Blind Program, Department of Special Education, San Francisco State University

To evaluate and teach one must understand normal speech and language development. That is, we diagnose the child's speech and language development as we teach; and, in turn, as we teach we can diagnose the child's speech and language development.

Instead of discussing the development of speech and language skills, I prefer to discuss with you the development of communication skills. I like the meaning of communication I learned in my linguistics courses: "interaction with the environment." By this definition all living things have the ability to communicate. Certainly, then, deaf-blind and multihandicapped children have the ability to communicate. Communication generally takes place between individuals, which in itself highlights the necessity of human stimulation if the child is to develop communication skills.

I will describe the stages in developing *receptive* communication skills—that is, developing an understanding of the environment—as well as the stages in developing *expressive* communication skills, which could be broadly said to relate to the environment.

Receptive Communication Skills

All parents, particularly mothers, soon recognize the differences in the crying of their own babies—the cry of happiness; the cry of discomfort; the cry that means: "You had better come quick, something's really wrong"; and the cry that means: "I just wanted to let you know that I'm still here and I'm lonely, and I want company."

The infant learns very early that crying can be used to gain control over his environment. This can be considered the beginning of expressive communication, since it is purposive.

The building blocks of language are the phonemes. There are two kinds of phonemes. The first type includes all the consonants and vowels of a language, and they are called the "segmental" phonemes. The other type of phonemes, the "suprasegmental" phonemes, includes all other aspects of the spoken language, such as pitch, rhythm, and intonation. We must remember that infants grasp the nature of what people are saying from the tones of their voices—from the suprasegmental phonemes—long before they understand the meanings of specific words.

Infants understand a lot and take in a lot from their environment before they begin to express themselves. It is important to remember how much the normal infant gets from nonverbal cues, such as facial expressions and body gestures, in addition to tone of voice.

Expressive Communication Skills

An infant begins to express himself or herself first by using all the suprasegmental phonemes of pitch, intonation, and rhythm and then, much later, by sounding recognizable vocabulary words. The infant experiments with articulators, particularly with tongue and lips, and enjoys listening to all the strange noises that can be made by moving the tongue around in the mouth.

The following tabulation is a complete outline of the acquisition of consonants by the normal child. There may be some modifications in the normal developmental sequence in any particular child, depending upon specific visual, auditory, motor and/or intellectual deficits.

By age:	*Sounds mastered are:*
Three and a half	/b/, /p/, /m/, /w/, /h/
Four and a half	/d/, /t/, /n/, /ng/, /k/, /g/, /y/
Five and a half	/f/
Six and a half	/v/, /th/, /sh/, /l/
Seven and a half	/s/, /z/, /r/

Adult Communication with Children

Adults should communicate as much as possible at eye-level with infants and children. Imagine what it must be like for the deaf child to have to walk around looking up all the time at adults' mouths and/or hands. The best way to establish communication is for the adult to repeat something the child already says or does. Imitating the child is a better reinforcer of behavior than always

insisting that the infant or child imitate what we are doing. For the deaf-blind and multihandicapped child, it is particularly important that any natural gestures and sounds be given meaning before a formal speech and sign system is introduced.

Learning should be fun. Sometimes parents and teachers find it hard to remember that "teaching should be fun" when they are faced with the day-to-day reality of coping with a deaf-blind or multihandicapped child

The adult should remember to keep the language simple—use single words and phrases—when communicating with the infant or young child. Also, describe each object and activity in several different ways.

The critical point to emphasize is that the adult must always use language which is at an appropriate level for the infant or child. One must always keep in mind that for the deaf-blind and multihandicapped child, one must think in terms of *developmental* levels, rather than chronological levels. In other words, use language that is appropriate to the developmental level of the child, instead of age level. Also, accept approximations of the child's attempt to use speech, gestures, and/or signs. Don't expect his expressive language to be exactly perfect; as long as the word, gesture, or sign is used consistently and is appropriate to the situation, accept it.

When the child begins to put words together, try to get the words in the appropriate order for your language. In English, for example, the adjective precedes the noun (as "big dog," "yellow car," "one ball," and "this house"); and the verb follows the subject (as "dog run" and "boy jump"). Remember that children do not use plurals, verb tenses, or possessives when language is first expressed; this should be kept in mind with respect to using Ameslan (American Sign Language) with the infant and young child. If a form of SEE signs (Seeing Effective English)—signs which add English syntax—is going to be used, it probably should not be introduced during the early stages of language learning.

Only when the sounds, gestures, and/or signs that the child makes by accident are responded to by those in his environment do they become words. If no one responds to the child's attempts to communicate, the child will stop communicating. I wonder how many "autistic-like" children reject those in their environments as a result of having been rejected.

Prevocational Training

Presented by Paul Small
Prevocation Specialist, Southwestern Region Deaf-Blind Center

Does the term "prevocational training" bring a flood of questions to mind when you think of the child or children with whom you work? Do you "turn off" because you rationalize that your children will *never* be able to enter the competitive world of work? Or do you say to yourself, Johnnie can't even tie his shoe yet, or Susie can't even write her name—or any one of a long list of "can'ts"?

Rather than using the term "prevocational" by itself, let's team it with "precareer." That way we are covering more ground and will deal more with the whole child and his life. The dual phrase, "precareer/prevocational" means the entire process of work readiness, from the development of appropriate toileting habits and personal care skills to the acquisition of desirable attitudes toward the world of work to having basic work skills which will contribute to eventual employment.

Rights of the Handicapped

Frank Laski, an attorney at the National Center for Law and the Handicapped, stated (1974):

> In the last few years in the United States we have become more aware of the influence of legal and civil rights upon the ability of handicapped persons to achieve appropriate status in society.

Those of us who are in the professions dealing with the education and training of deaf-blind children have an inherent responsibility to do everything humanly possible to foster and to ensure the right of deaf-blind persons to achieve their "appropriate status in society." A part of that right is the ability for the individual to make a contribution to the society in which he lives, be it through intellectual endeavors or manual performance, to whatever degree the individual is capable and has desires to perform.

The right is not only underwritten by our federal government and many state governments, but it was also ascribed to by the resolution adopted in 1971 by the General Assembly of the United Nations. That resolution, as paraphrased by Frank Laski (1974) to make specific reference to deaf-blind persons, reads:

1. The deaf-blind person has the same rights as other human beings.
2. The deaf-blind person has a right . . . to such education, training, rehabilitation, and guidance as will enable him to develop his ability and maximum potential.
3. The deaf-blind person has a right to economic security and to a decent standard of living. He has the right to perform productive work or to engage in other meaningful occupation to the fullest possible extent of his capabilities.
4. The deaf-blind person has a right to protection from exploitation.

Prevocational Preparation

The Southwestern Region Deaf-Blind Center recently conducted the second in a series of workshops for the purpose of gathering information in preparation for developing a precareer/prevocational curriculum for deaf-blind children. The persons contacted to participate in that workshop were state vocational rehabilitation personnel from Arizona, California, Hawaii, and Nevada, all of whom either have or have had deaf-blind clients. Ninety-eight persons were initially contacted; 34 persons responded based on the criteria for participation, and 28 persons were invited to participate. Fifteen vocational rehabilitation personnel were able to take part in the workshop.

The most significant prediction to be made from the information gathered is that, of some 50 deaf-blind clients presently on the caseloads of the 34 responding vocational/rehabilitation personnel, only four will be placed. That is roughly 8 percent—a very disheartening prospect. Other regions have predictions ranging from 10 to 14 percent.

The primary purpose of the workshop was to obtain information from the real situation of seeking, obtaining, and retaining employment for

deaf-blind individuals. The information obtained is by no means conclusive, but I feel it indicates why we need specific precareer/prevocational curricula in the programs serving deaf-blind children.

I want to share some of the material developed at that workshop. The following list identifies those factors (in the order of importance) which seem to contribute to the successful placement of deaf-blind individuals as determined by the workshop participants:

1. The ability of the deaf-blind individual to communicate on the job, express basic needs, and ask questions
2. Good self-image: positive self-concept, self-confidence, and a sense of humor
3. Independence, on and off the job, in caring for oneself, avoiding danger, toileting, and mobility
4. Receptiveness to learning new skills and flexibility in performing a variety of tasks
5. High motivation to perform on the job and to work a prescribed number of hours
6. Assertiveness in seeking and retaining employment
7. Family support, defined as allowing the deaf-blind individual to be trained and encouraging job seeking and placement
8. Degree of impairment: the less serious the handicap, the greater the chance for successful placement

Next I list, in priority order, the two elements that contribute most to the failure of deaf-blind clients in retaining employment:

1. Lack of family support: overprotection and the encouragement for dependency
2. Nonacceptance of the handicap by the deaf-blind clients: poor emotional adjustment as related to the handicapping condition

The next task performed by the workshop participants was listing difficulties and frustrations they have experienced in seeking placement and/or retaining placement for deaf-blind clients:

1. Lack of communication and knowledge. This included (a) lack of communication between employer and client, co-workers and client, rehabilitation counselor and client, rehabilitation counselor and employer, and rehabilitation counselor and rehabilitation team; and (b) lack of knowledge of the handicapping condition, skills necessary for the job, and employers' constraints and requirements
2. Lack of community awareness, resulting in low expectations for achievement, training, and placement (Note: "community" is defined as all-inclusive: home, school, general public, professionals involved with deaf-blind individuals, and employers.)
3. Lack of resources, additional training, and placement locations
4. Clients' lack of training in daily living and self-help skills
5. Inadequate transportation and housing (availability and location)
6. Inadequate (often incomplete) medical information regarding clients' handicapping conditions, medical history, and prognosis
7. Employers' lack of concern for on-the-job safety

The last prioritized list was of difficulties deaf-blind clients experienced in obtaining and retaining work placement:

1. Level of clients' competency going unrecognized by family, community, training center staff, and employers
2. Poor self-image: low motivation to learn and/or perform
3. Lack of opportunity for clients to enjoy successful experiences and upward mobility in jobs
4. Lack of communication and social interaction skills
5. Few incentives to work, due to inadequate benefits (pay and medical and other fringe benefits)

These lists were reviewed and reacted to by employers and supervisors of deaf-blind employees as well as by the deaf-blind employees. Although the numbers of employers, supervisors, and employees were minimal at this time, we felt their input was a vital part of developing these prioritized lists.

Program Recommendations

In contemplating a precareer/prevocational program for an individual child, a class, or a total program, I urge you to consider the following:

- Consider the child to be served.
- Consider the community in which that child lives or might live.
- Consider society's expectation of a "worker" as it might apply to the population with which you are dealing.

- Consider the jobs or kinds of work that are presently available and the kinds of jobs that could and should be available.
- Consider the personnel and resources available to you.
- Consider the amount of time, energy, and effort that will be required to put all the pieces together to develop a meaningful, worthwhile precareer/prevocational program that *must* meet the following three criteria:

  First and always foremost—the program must meet the needs and potential abilities of the deaf-blind individual.

  Second—the program must be geared to meet the needs and requirements of the employer.

  Last—components in the program must fulfill requirements of society.

Two of Prosser's theorems of vocational education (Walsh, 1975) apply directly to the development of a precareer/prevocational program for deaf-blind children:

1. Vocational education will be effective to the extent that it enables each individual to capitalize on his own interests, aptitudes, and intrinsic intelligence.
2. Vocational training will be effective to the extent that specific training experiences for forming right habits of doing and thinking are repeated to the point that these habits become fixed to the degree necessary for gainful employment.

An appeal to an employer's sense of social responsibility generally is not enough to persuade him to hire a deaf-blind person. It is our responsiblity to instruct and prepare the deaf-blind individual to perform in such a manner as to make him an asset first to himself, then to an employer, and then to society.

Peter Salmon, Director of the National Center for Deaf-Blind Youths and Adults, says (1974):

> Scarcely ten years ago, any employment of deaf-blind people was considered to be remarkable; and with the exception of a handful of highly superior individuals, the employment of the deaf-blind under fully competitive conditions was almost unheard of.

Let me describe a task, broken into steps:

1. Pick up a flat carton that measures about 1" X 1" X 3" (about the size of a cartridge film carton).
2. Open the carton.
3. Close one end of the carton by folding two side flaps and the cover. Turn the carton with open end in an upright position.
4. Pick up the object to be placed in the carton.
5. Insert the object into the carton.
6. Close the open end of the carton by folding two side flaps and the cover.
7. Place the filled and closed carton on the work surface.

The task? Packaging automotive spark plugs at the A.C. Spark Plug Division of General Motors Corporation in Flint, Michigan. It is being performed and has been performed for more than 30 years by a number of persons for eight hours a day, five and six days a week at scale union wages with all of the usual fringe benefits, hospitalization, paid vacation, and the like.

How many of you can envision the children with whom you work being able to perform that task as it was described? If you cannot convince yourself that a deaf-blind child can perform every step of that task, can you at least accept the idea of the child's being trained to do certain selected steps of that task and another child being trained to perform the remaining steps, thereby ensuring the successful completion of packaging? This is a saleable skill. This is a "can" situation as opposed to a "can't" situation.

Let me describe another work task in a very general way:

1. Grasp a pencil-shaped item.
2. Insert that item vertically, in a downward direction, into what resembles an electric pencil sharpener.
3. Withdraw the pencil-shaped item from the sharpener and place it on the work surface.

Western Electric and the Pacific Telephone Company refer to this process as "tool refurbishing." The job is the sharpening of drill bits, something that is generally not done by these firms because, in terms of their existing profit posture, it is not practical because of the cost of drill bits versus the cost of man-hours. However, this is a project that is being investigated by Western Electric and Pacific Telephone for sheltered workshops for the severely handicapped (including the visually-auditorially impaired) in both northern and southern California. If successful, the project will achieve several objectives:

1. Providing employment for severely handicapped persons, deaf-blind included
2. Helping to conserve natural resources
3. Contributing to the nation's economy through salvage of material and providing employment to heretofore unemployable persons

These are two specific competitive work tasks that deaf-blind individuals can perform, and the list of such tasks is endless. We just have to take the time and effort to sit down, list them, analyze what is required to perform those tasks, and train deaf-blind individuals to perform those tasks. I don't mean to oversimplify the process, but these are the necessary steps.

Precareer/prevocational/vocational training is a tremendous task that for too long has not been given its rightful place in the educational programs for the deaf-blind. Many of you have deaf-blind children fast approaching adolescence and adulthood. Now is the time to gather together the people and the resources necessary to provide the training and develop the attitudes that will enable the deaf-blind child of today to become the citizen of tomorrow.

As Herbert D. Nash stated (1974):

> Prevocational programs must be established to ensure transfer from special classroom programs to vocational training programs.
>
> Vocational training facilities must either be modified or developed so that the deaf-blind youth can receive and benefit from training.

Conclusion

I want to stress the importance of the need for everyone now connected with deaf-blind children or who is likely to become involved with those children in the future to come together to plan collectively and cooperatively for each child individually.

It is only through a unified, collective, cooperative effort that these kinds of programs can be developed for the deaf-blind youngster of today—the adult of tomorrow. To that end, the Southwestern Region Deaf-Blind Center staff is ready to assist you in any and every way possible. We cannot do the job for you, but we are ready to assist you in any way that you feel is appropriate and within the realm of the possible.

You are the prime doers. Your children are the prime benefactors. Your community is the ultimate judge of your efforts.

One word of caution: Do not let anyone oversell you on generalizations. You are unique, you are all individuals. Your children are unique, they are all individuals. Your communities are unique because of the grouping of unique individuals with their own personalities, customs, likes, dislikes, and available resources—natural and man-induced.

Retain your uniqueness. Build on your particular strengths in attempting to take on some other already developed program in toto. You may be introducing factors into your programs that will not benefit your children and may, in fact, be detrimental to your program.

Don't be afraid to use what you know, intellectually and intuitively. Look inward. Look around you. You have many things to offer.

Bibliography

Laski, Frank. "Basic Legal Aspects of Planning for Deaf-Blind Persons," in *1980 Is Now*. Edited by C. Sherrick. Los Angeles: John Tracy Clinic, 1974.

Nash, Herbert D. "The Silent Child and the Squeaking Wheel Syndrome," in *1980 Is Now*. Edited by C. Sherrick. Los Angeles: John Tracy Clinic, 1974.

Salmon, Peter. "Some Observations on Services for the Deaf-Blind," in *1980 Is Now*. Edited by C. Sherrick. Los Angeles: John Tracy Clinic, 1974.

Walsh, John P. *Polarizing Educational Effort*. The Samuel Leonard Fick Lecture on Industrial Education, Thirty-seventh Annual Conference on Industrial Education, San Francisco, March, 1975.

Home Programming in Isolated Areas

Presented by Dottie Tehan Young
Outreach Teacher, Navajo Tribe, New Mexico

The Navajo Reservation is located in the four corners region where the states of Arizona, Colorado, New Mexico, and Utah converge. The reservation encompasses an area of 25,000 square miles and is about the size of the state of Virginia. The land varies from desert to high mountain pine areas. The Navajo people have been in this area for about 500 years, and for many years before that other cultures inhabited the area, so the area is rich in culture and heritage.

Today there are about 140,000 Navajo people living on the reservation, scattered over this wide area, living in small groups of extended families. Lifestyles vary, but many of the people live in small, one-room homes called hogans. Their livelihood comes mainly from their occupations of sheepherding, farming, silver work, and weaving.

The living conditions are not ideal. Eight towns are located on the reservation, but the majority of the people live in scarcely populated areas. There are very few paved roads, and it is not uncommon for a family to travel 50 to 60 miles to get to the store or hospital. Not many dwellings have running water or electricity. The average income for most of these families is less than $1,000 a year, and unemployment due to lack of work opportunities is high. Problems such as poor nutrition, poor health, disease and illness, poor prenatal care, alcoholism, and many other problems of social neglect are common. Life is not easy.

Problems from Cultural Differences

Many cultural problems are a result of what I would call a conflict of values. The Navajo people have a strong culture. Their heritage and traditions thrive and, for many, make up the basis of their lives. The medicine man continues to play a vital role in the welfare of his people; ceremonies and blessing rites are important and serve as ties between the past, present, and future. Communication and family life styles have a distinctive nature. Navajo is the primary language for most of the people.

Conflict begins with the many government agencies that provide services to the people. Most of these agencies are directed by people of white middle class backgrounds who are often insensitive to the Navajo's culture and life. How does one equate the Navajo medicine man and his work with the medicine of the white Anglo world? How does one handle the differences between the Navajo culture and the Anglo educational system? How does one reconcile the difference between the Navajo concept of time and future and that of the Anglo world?

These differences have taught me important lessons since I began to work with the children and their families. It has been necessary for me to try to understand the unique culture of the Navajo people. After all, a home teacher is one who teaches in the home and shares in each family's lifestyle.

Program Outreach

The deaf-blind Outreach Program of the Navajo Division of Special Education began two years ago. It was started as a means to provide some type of direct service to the many multihandicapped children that it was believed existed and were being cared for in their homes. The many children on crippled children's rosters made the need for home programming obvious. Today the program is funded by the Southwestern Region Deaf-Blind Center. The purpose of the program is to provide direct services to deaf-blind multihandicapped children and their families. At present, the project consists of one teacher, myself, who sees children in an area covering about one quarter of the reservation.

My caseload consists of 29 children and their families. The children range in age from twelve months to fifteen years. Their handicaps vary greatly, many children having three or more handicapping conditions. The children are visually impaired, hearing-impaired, mentally retarded; have cerebral palsy, seizure disorders, communication disorders, and so on. Most of the children were referred by nurse practitioners and physicians

in the many hospitals and clinics on the reservation. Several children have been referred by families being seen. One mother said she knew of two more little girls like her own, and we went to meet them.

My caseload was ideal when I saw only about 15 children and was able to visit each child about once a week. With 29 children it is difficult to see the children that often. I still try to see the young severely handicapped children weekly. The less severely handicapped children I see biweekly, and I work hard to try to place them in some of the existing services, such as Head Start. The large number of children to be seen certainly has decreased the quality of programming provided.

The home program is unique to each child and the child's family. Initially it was important to get to know the child and his or her family together, and our first conversations revealed much useful information for all of us. Many of the parents had to get over the fear that I was there to ask them to institutionalize their child. Apparently this has happened often in the past. From our first conversations I gain an understanding of the parents' interpretation of their child's handicaps and their hopes and expectations for the child's future. And they learn more about why a teacher would come to their home.

With the parents' help, we do a Callier–Azusa or Alpern-Boll developmental scale. From that a clear picture of the child's progress emerges, and together we develop useful goals. For many of the families, this revolves around the child's learning basic skills such as sitting, walking, chewing, and feeding himself or herself. Certainly, finding ways to make life easier and better for everyone helps the whole family situation. In doing this I am most comfortable with a developmental approach. When we find out what their child can do, then I can help the parents recognize what the next step should be.

Because of the children's many basic needs, there is a great need for parent education. What is the best way for a mother to try to improve head control, so that one day her little girl may sit up? Is there a better way to feed a little girl than to have her lying on the bed? If so, why is it better? Are there toys that can provide stimulation to a little girl lying in her crib? Are there exercises that a mother can do to increase the range of motion of her daughter's fingers and hands? Why is it important for Carlos to drink from a cup?

We talk about all of these things and more. Through our talking and demonstrating, the parents learn many little things that help their child, and I get new ideas from the parents. During this talking and working with the child and the parents, we share a lot of support and concern. Home teaching is often 50 percent working with the child and 50 percent supporting the parents. Giving the parents the support and encouragement they need to cope with such great difficulties is equally as important as working with their child. It will be a long haul for them in the days ahead.

One pleasant sidelight of the program has been the parents' increased awareness of general child development and how their children learn. Many good toys and adaptive equipment have been made which have greatly benefitted other brothers and sisters as well.

In one area where several children are centrally located, we have started a weekly mothers' group, which has become pretty successful. Each Wednesday morning, about seven or eight of the mothers get together. We have spent these sessions in different ways, such as watching a film on child development or on a program for handicapped children, hearing a nutritionist speak, learning about the different types of car seats available, and arranging babysitting services. I think the most valuable part has been the mothers' sharing and interaction with each other. It is good to know that someone else has similar feelings and problems! We have also had several suppers and cookouts at night so that the fathers and the rest of the family could join in, too.

Weaknesses of the Program

I think I should be honest and say that there are several weaknesses to this program. First, there has been a general lack of existing services for handicapped children on the reservation. The family has been the sole support for the child. Fortunately, next year will bring some changes with more educational programs that will accept the severely handicapped child, and several good area resource center groups will be starting for the parents.

Second, Outreach is an expensive program. The distances between children's homes are great, so there is much driving to be done. I usually average 800 miles a week. Driving time certainly cuts down on the time spent with the children, but when there is no other way, driving long distances becomes necessary.

A third weakness is that it is difficult to work alone. Just as it is important for parents to get together and share with each other, so is it also important for teachers. Not many people have

been interested in the severely handicapped child and his family. In a center or training school, there are many other people to share with and learn from, and each provides inservice for each other. Outreach teaching can be isolated and lonely at times. Very few ancillary disciplines such as o.t., p.t., speech therapy, and so forth have been available to provide me, as a teacher, with support. Going to conferences, receiving newsletters, and keeping up with new ideas and materials have been important.

The final area of difficulty has been my being from another race, another culture. At times the language barrier has been difficult—a person who is Navajo could be much more effective. At this time there are several Navajo students preparing in special education, and I hope they will someday be the teachers. Meanwhile we do the best we can.

I will end by saying that the near future looks terrific! We have received funding from the Bureau of Education for the Handicapped to start a preschool for severely handicapped children in one area of the reservation. The parents are thrilled. Also we have applied for an increase in our funding from the Deaf-Blind Regional Center to serve the other three-quarters of the reservation. We hope to have five Outreach teachers next year.

Working with Parents

I wanted to share with you some experiences I have had with parents of handicapped children and some lessons I have learned from them. I have come to realize that parents are the most important force in a child's life. Certainly, they are their child's *first* teacher. I have learned that I need to be much more understanding and sensitive to their situation and to what it means to be the parent of a handicapped child. I have also realized that the parents are entitled to as much support as their child.

Stop and think about parenting today. Certainly, it has become a popular topic. We hear about and read about it everywhere. The *Reader's Digest, Woman's Day,* and the daily newspaper carry articles about parenting in almost every issue. It has become a big business, generating courses and books about subjects like parent effectiveness training. I do not think that we as teachers can ignore all the media that are available to parents.

Stop and think about what it means to be a parent of a handicapped child. To begin with, let's reflect about the hopes and dreams all parents have for their children. No one anticipating the birth of a child chooses to be the parent of a handicapped baby. Nor when the baby is born do parents suddenly become equipped with the strength and patience and hope they will need for the many long days ahead. Have you stopped to wonder how you would do? Think, too, about the training and people you have been exposed to and how much you have learned about a child who is handicapped. Who has been there to teach the children's parents? Usually the most important resources they have had are their own love and intuition. Perhaps these are the most important resources of all.

Because of the wide age range of children, many of the parents I work with have expressed different feelings and reactions. I began to realize that my plans and expectations were sometimes very different from those of the parents. Why was there that difference? How come we were not talking about the same thing? Why were the parents so worried?

I began to realize that as a teacher I was an outsider. Certainly I was concerned. I could look at the child and acknowledge his handicap. But I was removed and not really involved. Not so for those parents—they lived with that child day in and day out. I saw the child for several hours and usually under ideal circumstances. It was here that our communication often broke down. Why?

Learning about feelings and stages of acceptance and growth has helped immensely. The work of Elisabeth Kubler-Ross and her book, *On Death and Dying,*[1] greatly increased my understanding. It is important to think about their hope for a normal child. Just as we grieve when someone we love dies, so, too, do parents of a handicapped child grieve over their loss. Grieving is important, and most of us cannot grieve alone. Some parents grieve for a short time and seem to move on. Others may mourn for the rest of their lives. Many will be in between. How do we as teachers react to this?

The ultimate role for everyone on the long road ahead is acceptance and the realization of his or her child's handicaps and also of that child's potential. But oh, it is a long process to go through, and how painful!

Many believe that there are several stages in the acceptance process. They are denial, anger and guilt, hope, depression, and finally acceptance and understanding. We all experience these feelings, and we often bounce back and forth between

[1]Elisabeth Kubler-Ross, *On Death and Dying.* New York: Macmillan Co., 1969.

them. It is only normal. Do we realize and recognize that process within the parents?

The following is a brief outline of feelings parents and professionals may experience in growing to accept a child's handicap.

1. *Denial.* We choose not to accept the realization of the child's handicap. *(This couldn't happen to me. . . . How could that doctor know? . . . There's nothing wrong with her.)*

2. *Anger and guilt.* We accuse ourselves and others. *(What did I do wrong? . . . Why me? . . . The obstetrician was at fault. . . . I can handle this by myself. . . My husband says if I had only done this . . . Why didn't anyone help me from the start?)*

3. *Hope.* We usually experience this to an excess, in an unhealthy way. *(Someone told us Dr. Jones might help. . . . I read in* Reader's Digest *about this child. . . . We're going to a faith healer.)*

4. *Depression.* We experience the blues and sometimes withdraw. We are down in the dumps for a long time. *(I never get out of the house anymore. . . . My relatives never come to see us anymore.)*

5. *Acceptance and understanding.* We realize the reality and try to cope in our own way. *(I know he can't see. What can I do to help him get around the room? . . . She can't hold her head up. But can I fix the high chair so I can feed her in it? . . . He's different from his brother, but we love him too!)*

What does all of this have to do with teaching? Plenty! How often have you heard a teacher say things like this?

Carol's biggest problem is her mother!

I'm so mad at those parents.

I wish there was more follow-through at home.

Jim's dad thinks he's going to grow up and go to college.

Mrs. Smith still feeds her from the bottle because it's easier.

Tommy's parents just don't seem to understand what's really wrong with him.

I've given up on them.

Can you hear yourself saying things like these? We have all had our moments.

If we could only remember that we are teachers only five hours a day and that the parents are parents of these children all their lives, our sensitivity would greatly increase. Perhaps if we knew the parents a little better and tried to understand their feelings, out whole communication process would improve, and ultimately their child—our student—would benefit.

Atypical Development

Presented by Cathy Callahan Groves, M.A.

I have decided to narrow the topic of atypical development considerably and to focus on those behaviors that are variously referred to as self-stimulating, autoerotic, and self-abusive. These behaviors may be labeled as "blindisms"; oftentimes they are viewed as being perseverative in nature.

It is my impression that our interest in, and concern about, these behaviors directly result from the failure of traditional methods prescribed for dealing with these behaviors. These traditional methods have typically had the goal of extinguishing the behavior that is considered to be self-stimulating.

I am not opposed to the use of extinguishing, modifying, and shaping techniques with self-stimulating behaviors; however, if we are to use these techniques responsibly, we must first make a careful study of the child's behaviors in light of that particular child's developmental patterns. As this study of the child ensues, a variety of approaches to the child's behavior may be developed.

The key is to understand the behavior from the child's experience of it. It is from these fragments of understanding that we can evolve developmentally appropriate intervention techniques. This is a speculative process and most certainly subjective. The "objectifier" in this inferential venture is a solid grounding in, and appreciation of, normative development. This is a big order, for there are normative sequences and profiles for all areas of development—most of which may be classified under object relations development, cognitive development, and social development. (Ginsburg and Opper, ed., 1971; Brazelton, 1969; Mahler, 1975; and Mussen, 1974)

The various developmental perspectives may not always seem complementary. For example, what seems well-grounded for the child educationally may not seem wise from a psychological or physical point of view. It is crucial that we learn from the various disciplines and team members of other professions in order to ensure our attention to the child's total system and to avoid meeting one set of needs at the expense of another set.

S., for example, is a boy five and a half years old. He has just learned to walk independently, using a very broad-based gait. He has no expressive language in the form of signs, signals, or vocalizations. Currently he is in a preschool for the deaf-blind. The family and staff have pinpointed toilet training as a priority for instruction, but S. is evidencing great resistence to this training. The family and staff have noted a surrender of some of S's acquired motor skills.

This case synopsis is not meant to shed a disparaging light either on the art or on the accomplishment of becoming toilet trained. It is meant to suggest that the introduction of toilet training may have been ill-timed.

In our eagerness for the child to arrive at developmental performance milestones, we may overlook some other kinds of developmental needs that are not so concretely evident as are needs for behavior acquisitions. Children also have some abstract needs such as the need for trust and autonomy. These needs are met for normal children in rather conventional ways. Handicapped children have these needs, but we may not recognize them as easily as we recognize and attempt to satisfy the children's obvious need for skill building.

In S's case, he may have perceived the effort to toilet train him as a restriction of his one budding area of developing competence—free motor movement. He finally had achieved an ability to *leave* a situation, and now he is being confined by the toilet. Additionally, S. had no way of expressing autonomy except through resistance. The classic "No, it's mine!" in the form of language was not in S's repertoire. S. may have decided that if he were to surrender his motor skills that he could be allowed again the freedom of infancy—to deliver his excretory products where and when he wanted to.

Alternatives to this plan of action might have been:

1. A delay of the toilet training until S. had more time in the exercise and refinement of his developing motor skills.

2. A construction of situations in which S. truly had a choice and could indicate the choice through a pushing away of the unwanted food or toy. At this time the sign, signal, or vocalization for "no" or "no-want" could be introduced.

Perhaps with this introduction of arenas for the exercise of autonomous choice and functioning, S's toilet training would not need to be an area for the exercise of autonomy. With toilet training accomplished at the expense of "will" development, there is no victory for this child, even though his performance record may reflect it.

Certainly S's case would not be applicable to all children. For some children the delay of toilet training expectations and instruction may be developmentally ill advised, in which case it would need to have a priority focus. Each deaf-blind child is different in his or her level of functioning and developmental needs.

Developmental sequences and needs again come to the forefront when we view self-stimulating behaviors. Let us examine possible explanations for the evolution of these behaviors:

1. *An originally adaptive attempt to meet a developmental milestone.* Eye-pressing and the posture of the hands fisted at the eyes might be considered from this point of view. Picture a sixteen-week-old blind infant lying in a crib. Arms and hands are involved in random movement at the infant's sides. By chance both hands make contact through this random movement. Maybe the blind infant does not sense that these "things" touching each other really belong to him or her when they are touching each other out and away from the body. Unlike the sighted child, the blind child does not become visually fascinated by mutual hand play. Rather, this child may bring those touching hands into the center of self, the head, and in this manner may better "know" these touching hands as part of himself or herself. What if the small and fisted hands are placed on the eyes? Aha! A flash of light results. Not only does the blind child learn that indeed these touching hands are part of self, but also that they can make things happen in a cause-and-effect way: they can make light happen. To have a role in making things happen is a reinforcing experience. This behavior, viewed through the adaptive attempt framework, changes our understanding of the behavior and gives us possibilities for intervention that might have been overlooked had we pulled the child's hands from the eyes for manipulation of an object away from the body plane.

2. *Defensive self-stimulating behavior.* If a child's central processing abilities (organizing and making sense of sensory input) are deficient, that child may develop behaviors that prohibit the entrance of overwhelming and unorganizable stimuli into his or her awareness. Additionally, a child with a particularly sensitive sensory modality may protect himself or herself from being overstimulated by refusing to use this particular sensory modality. Behaviors often described as "autistic-like" may fall into this category.

An interesting function of these behaviors may be that they not only serve the child as a defense against stimuli the child may be unable to organize, but they also may help the child digest and make sense of those stimuli that are allowed in. It is possible that these behaviors become regulating devices for the child.

3. *Increased stimulation in a reduced sensory environment.* Another explanation, and perhaps the most familiar one, is that regarding the self-stimulating behavior evolving as a result of decreased sensory input from the external environment. From this perspective, if sensory stimulation is decreased, the child may generate stimulation in order to keep the system activated. External stimulation is less available on an incidental and distal basis for deaf-blind children. Therefore these children develop repertoires which provide this missed experience, and they occupy themselves with proximal and self-induced stimulation.

Though self-stimulating behaviors may have evolved as a result of one or more of the proposed explanations listed above, it is hard for us to determine the origin of the behaviors. We usually see the child long after the behavior has served its original purpose and has developed into a habit.

We are well advised to consider the following questions prior to intervening in regard to the self-stimulating behavior:

1. What are the possible purposes served by the behavior for the child? (Remember the child's perspective.)

2. Are particular modalities involved in this stimulation?

3. Are particular modalities avoided in the self-stimulating behavior?

4. How can I enter into the behavior to see if I can learn from it and possibly change it?

5. How can I change the stimulation I offer so it does not need to be blocked out by the behaviors?

Many more appropriate questions need to be posed in regard to these behaviors. I hope that the above-mentioned ideas will stimulate the generation of your own questions about these behaviors and consequent intervention techniques.

Bibliography

Piaget's Theory of Intellectual Development: An Introduction. Edited by Herbert Ginsburg and Silvia Opper. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1971.

Brazelton, T. Berry. *Infants and Mothers: Individual Differences in Development.* New York: Delacorte Press, 1969.

Mahler, M. *The Psychological Birth of the Human Infant.* New York: Basic Books, Inc., Publishers, 1975.

Mussen, Paul H., and John J. Conger. *Child Development and Personality* (Fourth edition). New York: Harper and Row, 1974.

Creative Play: A Vital Learning Experience for the Young Deaf-Blind Child

Presented by Carol Stensrud
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Play is more than a child's response to life—"It is his life, if he is to be a vital, growing creative individual." (Gregg, 1968) Through play a child learns who and what he is, what he can do, and how he can relate to the world in which he lives.

Many authors indicate that play is the way a child learns what no one can teach him. For the young deaf-blind child who has so much to learn and is limited in communication skills, learning is a slow and often difficult process. Parents, educators, recreators, and other specialists are often frustrated working with this young child, for they feel unable to find a workable method by which to reach him. If play is truly a means to teach children what cannot be taught in the "normal" manner, then play could be one of the greatest avenues of learning for the deaf-blind child.

Play is fun. Everyone has a need to play. Play is especially important for the young child because it is a primary learning opportunity. The play experience influences the child's total growth: physical, mental, emotional, and social. Through play the child strengthens his muscles, develops his coordination, and sharpens his senses (sight, sound, smell, taste, and touch), all of which are essential for learning. Play stimulates creativity and the use of imagination. It aids in the development of problem-solving behavior. Play also helps the child develop awareness of self and others. Through play the child learns to get along with people and to develop attitudes, emotions, and feelings towards them and himself. (U.S. Department of Health, Education, and Welfare, 1973) Susan Isaacs, a British educator, found in her observations of children's unstructured play situations that play leads to discovery, reasoning, and thought; is a bridge to social relations; and leads to emotional equilibrium. The literature reveals that play is a successful method through which children learn about themselves and the world around them. (Matterson, 1973)

Adults working with young deaf-blind children must realize the role that play assumes in the educational process of these children. When the adult is aware of the importance of play in the child's total development, the adult can help in the child's physical, mental, social, and emotional growth by assuring that the child is provided with both unstructured and structured creative play opportunities. These experiences will be stimulating learning experiences for the child.

How can you aid the child in his or her play experiences? The following suggestions may give you some ideas on how to help the deaf-blind child realize the most benefits from play.

1. *Remember that children's growth has direction.* The deaf-blind child needs to be guided towards new play experiences. The child may not see the mud to play in or be driven by curiosity to investigate a front yard sprinkler party because he or she does not hear the laughing voices of the other children. We must guide the child to the play experience and then assume only as much leadership or direction as needed to assure the child's safety. The child will learn to problem-solve and develop creativity if allowed to engage in self-directive play. Adult-directed play impedes the child's self-paced learning through play and usually exercises only the adult's brain, not the child's.

2. *Realize that growth through play has order.* This is very important to remember: children should not be rushed into experiences they are not ready for. If a child is not socially ready to relate to another child or group of children, he or she should be encouraged to play and explore in the changing and expanding environment and gradually be introduced to peers. If a child is not ready to paint with a brush, finger paints will provide the child with a stimulating and appropriate play experience. The old "sink or swim" lesson is not the way to help young deaf-blind children to develop.

All activities must be sequentially introduced to assure the most benefit to the child. Give the child the chance to experience to the fullest and to learn and succeed at his or her own rate and time. A

child who is not ready to swim may be ready to wade, play in a bucket of water, blow bubbles, or play in the sprinkler. Children will communicate to you when they are ready to progress to another level of play.

3. *Assume the eyes of a child.* When you can relate to children on their own terms, you will be able to understand their needs and desires of play. What is fun for the child may be only messy, noisy, or dirty to you as an adult. "All children destroy before they create" (Matterson, 1973). Young children delight in taking apart an object and exploring its parts. They begin to understand the environment and the things in it through this process. The young child also needs to create. Raw materials such as mud, clay, wood, paint, and paper offer children the unstructured play experiences they need. Both creative and destructive play opportunities tend to be unstructured and quite messy. You, as an adult, must remember that you once engaged in this kind of play. Tolerance can be developed if you are truly willing to give the child whatever he or she needs to become a well-developed individual.

Possibly you have forgotten the joys of mud, water, bugs, leaves, dressing up, building crazy houses with boxes, or screaming with delight. Join the child at play and you chance being consumed by the activity, chance a growing experience, chance having a truly joyous, shared play experience.

4. *Adapt the play opportunity to maximize the deaf-blind child's total experience.* In analyzing a play experience, we look at what skills are required by the participant to engage in the activity (Avedon, 1974). Playing is experiencing; it is not passive watching. If the activity requires sight and hearing abilities for participation, we must find ways to adapt the activity so as to make the activity accessible to deaf-blind children through senses of touch, taste, smell, and residual sight and hearing.

How valuable is a trip to the zoo if the child is not allowed to be close enough to touch the warm fur of an animal or to smell the hay? A phone call in advance will usually open many doors of experience to your deaf-blind child. In my experience, most people will make necessary exceptions to the rules to afford deaf-blind children a chance to play in their own manner.

Every activity can be adapted to be more accessible to the deaf-blind child. We must utilize our creativity in an effort to provide the deaf-blind child with creative play experiences that are going to meet needs. Why paint with paint? Why not make it a tasting, smelling, and tactual experience by using peanut butter, margarine, pudding, and cornflakes? Why paint on paper? Why not develop body-awareness by painting our feet and face?

We are challenged to guide the young deaf-blind child towards creative, fun, and educational play experiences. In meeting this challenge, we are assuring the child the realization of the child's fullest potential, and we are afforded the chance to experience with the child the joys and sense of freedom that play brings to us all.

Bibliography

Some of the books that you may find helpful in stimulating your own creativity and in guiding children in their play are the following:

Avedon, Eliot. *Therapeutic Recreation Service:* An Applied Behavioral Science Approach. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1974.

Big Rock Candy Mountain, Resources for our Education. Edited by Seymour Lawrence. New York: Dell Publishing Co., 1972.

Caney, Steven. *Play Book.* New York: Workman Publishing Co., 1975.

Toybook. New York: Workman Publishing Co., 1972.

Caplan, Frank, and Theresa Caplan. *The Power of Play.* New York: Anchor Books (Doubleday & Company), 1973.

Correspondence Learning Program for Parents of Preschool Deaf-Blind Children. Los Angeles: John Tracy Clinic. [n.d.]

Gregg, Elizabeth M. *What To Do When There's Nothing To Do.* New York: Delacorte Press, 1968.

Hartley, Ruth E., and Robert M. Goldenson. *Children's Play.* New York: Thomas Y. Crowell Co., 1963.

Koberg, Don, and Jim Bagnall. *Universal Traveler: A Soft Systems Guide to Creativity*. Los Altos, Calif.: William Kaufman, Inc., 1972.

Marzollo, Jean. *Learning Through Play*. New York: Harper and Row, 1974.

Matterson, Elizabeth M. *Play and Playthings for the Pre-School Child*. Santa Fe, N.M.: William Gannon, 1973.

Palmer, Bruce. *Making Children's Furniture and Play Structures*. New York: Workman Publishing Co., 1974.

Play. Publication No. (SRS) 73-23009. Washington, D.C.: U.S. Department of Health, Education, and Welfare, 1973.

Porter, Jerry. *A Recipe Book: A Perceptual Potpouri*. Los Angeles: County Department of Parks and Recreation, 1976.

Program Development in Recreation for the Deaf-Blind. Edited by John Nesbitt. Iowa City, Ia.: University of Iowa, 1974.

Skakesby, Paul. *Child's Work:* A Learning Guide to Joyful Play. Philadelphia, Pa.: Running Press, 1974.

The Deaf-Blind Child—A Sexual Being

Presented by Jan Neff
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Traditionally, the sexual feelings of retarded and handicapped youth have been regarded as something that should not be there. Even those young handicapped people who are capable of attaining sexual maturity and becoming satisfactory marriage partners are too often blocked in their emotional growth and treated as nonsexual entities.

The schools reflect the fears, prejudices, and biases of society in general. Teachers and parents alike are of the same cultural background, and a generation of adults who have grown up in a society frightened of sex find it difficult to help children reach sexual maturity. As a result, teachers have not been adequately prepared to teach in this subject area. They are very limited in the means of obtaining the needed preparation, and thus the existing human sexuality programs have been extremely limited in scope and content.

The popular methods of dealing with sexuality in children have been to deny its existence and to suppress the behavioral manifestations of its existence. Many assume that in the absence of direct instruction, no sex education takes place. However, the way parents (or other significant sex models) regard themselves and behave, parents' reactions to each other as sexual beings, their attitudes toward toileting habits, whether or not they hide their bodies, and their ability to express love for each other and for their children all profoundly influence a child's sexual conditioning. Rejection, suppression, avoidance, embarrassment, and shock are all negative forms of sexual education. Therefore, we cannot choose whether or not we will educate children in sexual matters, but only whether our approach is positive or negative, whether we accept or deny our responsibility.

More and more people who work with handicapped children and adults, especially those with auditory and visual impairment, are becoming aware of the problems that are a direct outgrowth of the unfortunate lack of sexuality education programs. Concerned individuals are asking, "What can we do to remedy the situation?"

I feel that there are several things that we can and must do if we hope to find solutions to these problems.

It should be remembered that sex is something we are, not something we do. It is a major aspect of personality rather than merely a physical expression. It encompasses one's emotional, social, and cultural growth as well as one's physical development.

We must acknowledge that sexuality education for handicapped persons—adults as well as children—has been considered a taboo subject. Where a handicapped child has been given any formal sexual instruction at all, whether at home, at school, or elsewhere, it usually begins and ends with physical development and reproduction information. When adolescents need to deal with sexuality in terms of human interactions or as an aspect of relating to others, they are left entirely on their own.

Almost without exception sex education is thought of as some sort of protection against disaster—against what might happen. If parents, teachers, and others could be assured that no "trouble" would occur in the sex lives of children, most would feel no need whatsoever for any sex education. The fact that such a learning experience might enrich children's lives, making them more understanding of themselves, their families, and society is usually not even a consideration.

We must recognize that deaf-blind children and adults, like all other humans, are sexual beings whose physical handicaps create unique educational needs in this area. Although the objectives of a responsible human sexuality program for deaf-blind youth are basically the same as those for the nonhandicapped, the manner in which we seek these objectives may differ. Because of the many contributing factors, a sexuality program for deaf-blind youth must be much more of a remedial program than one for those who function nor-

mally. Also, the negative means which are utilized in dealing with the sexuality of normal children are greatly increased when it comes to deaf-blind children. Unfortunately, this often happens as the result of an adult's affection and concern for the child. Thus, we must never make the assumption that age is a key to the deaf-blind child's level of understanding.

To illustrate, allow me to share some data collected from my growth and development classes. Although none of the students are in the deaf-blind department, three have a serious hearing loss in addition to their blindness. Ten girls and nine boys from fourteen to twenty years of age were interviewed regarding sex-related words. Following are a few of the words from the list and the number of students who understood them:

	Understood by	
Masturbation	3 boys	3 girls
Pubic hair	3 boys	2 girls
Menstruation	1 boy	5 girls
Sperm	3 boys	3 girls

Virtually no one had any idea what orgasm or clitoris meant. One girl who had been raised by her grandmother knew the meaning of menopause.

Some of the responses to the meaning of the word *sperm* were: "It comes out of the penis, then there is a chemical change and it changes into an egg." "All I know is that they are alive, what they're for I don't know, but they come from egg cells." Or "Sperm is in the penis. It squirts into the vagina but I don't know why or what they are or what they do there."

We must be aware of the fact that it is never too early to begin the purposeful sexuality education of any child, especially that of a deaf-blind child. It has been shown that the sex education of human infants begins almost at birth through involuntary nonverbal communication, such as the way the infant is held and conscious or unconscious expressions of acceptance, rejection, love, or intolerance within the family. It is generally felt that young children are not able to comprehend sexual information. That has not been my experience. After my class of seven-to-nine-year-old blind students had been given several lessons on conception, one boy volunteered that he could not have any more brothers or sisters because his mother had her tubes tied. Another child raised his hand and asked, "Could my father get together with another female and make a baby?" I replied that I believed he could answer his own question. He then said smilingly, "Yep, they could!" At this point a little girl asked, "If my father had his tubes tied and the sperm couldn't get out, could my mother and another man make a baby?" My reply was the same, and several children echoed, "Yep, they could!" Throughout the school year these young children have listened to the lessons intently, asked meaningful questions, and made responses that are usually surprisingly sophisticated.

Some of you may feel that it is wrong to teach children these things. However, several students at our school who have reached the age of twenty-one and have not had the benefit of the growth and development classes think that if a male and female are not married they cannot have a baby. Also, several teenage former students gave birth to babies that they cannot now adequately care for because of that kind of thinking.

In helping the deaf-blind child understand the complex concepts of sexuality, one must be completely honest and straightforward at all times.

While attempting to develop the sexuality concepts of deaf children who are also severely visually impaired, we must not ignore the fact that the sense of touch is one of the most valuable learning tools that can be employed. At between eighteen months and two years of age, sighted toddlers have repeatedly compared visually and then contemplated the anatomical features of their parents' bodies, their own bodies, and those of sisters or brothers. Only through early and continual conscientious efforts of parents and other persons they are in close contact with, can deaf-blind children hope to develop the essential concepts of sexuality. Toward this end various family members can take turns repeatedly bathing with the young child, encouraging body exploration accompanied by a constant flow of information, and game playing accompanied by all manner of communication (words, gestures, signs, touch, and finger spelling). Just as the child is encouraged to "find" his nose, ears, and toes, he should also be encouraged to explore each and every body part, not only on himself but also on other family members, while simultaneously noting differences in anatomy as well as variation in size and shape. By working consistently with young deaf-blind children in this way, we can eliminate many of the anxieties the adolescent group must now cope with. Without the freedom and encouragement to explore their bodies, children have no hope of understanding how it is put together, how it functions, and how it differs from that of the opposite sex or even that there are sexual differences.

As soon as a deaf-blind child enters a program, whether it be preschool, kindergarten, day care center, or residential school, the teacher should immediately try to determine the extent of the child's self-awareness and sexual understanding and then initiate a course of study designed to meet that child's needs. Usually the child has not received directed sexuality instruction during the early formative years and is thus already years behind nonhandicapped peers in sexuality development. Based on information gained from my growth and development students—whose ages range from seven to twenty-one years—it appears that the older the handicapped children get before receiving directed, intentional sexuality education, the more difficult it becomes for them to comprehend even the most seemingly basic concepts. I feel that the young children are more able to form accurate concepts because they have fewer established misconceptions and inaccuracies. The older students do not disregard all that they have previously "learned" when finally given the facts. It appears that the facts only add to the complexity of their misconceptions.

Having determined the deaf-blind child's level of understanding, a teacher can engage the student in guessing games, tactual games, cuddling, stroking, wrestling, or swimming planned to further sexuality development while the teacher is in the process of teaching other skills. Doll families corresponding in size and number to the child's own family can be made from old wig forms, male and female wigs, stuffed panty hose, and so forth. Anatomically accurate rag dolls and department store mannequins can also be helpful in building concepts. The use of these dolls and mannequins enables the child to make comparisons regarding anatomical differences, body size, and clothing differences; to understand how children are conceived; to learn how to wear different types of sanitary napkins; and also to role-play a multitude of situations that can be guided by the teacher in order to further the child's sexuality awareness.

When deaf-blind children become curious about sex-oriented items such as clothing worn by the opposite sex and various types of sanitary protection, or how a child is conceived or how a baby is nursed, take advantage of these "teachable moments" and give them the opportunity to explore these items and activities by means of all of their functioning senses.

I would like to share with you one such "teachable moment." A few weeks ago one of my thirteen-year-old deaf-blind students came into the crafts room and said he would like to draw. He proceeded to draw a nude male with a great erection lying on a bed. He wrote his name on the figure. He then drew a nude female lying on top of the male with the penis of the male figure inside of the female's vagina and then wrote my name on that figure. At that point he had second thoughts, crossed out his name and wrote the name of a totally blind and profoundly deaf male classmate. This I ignored. Through drawings, gestures, and spoken words, I told the boy that I could not make a baby with him because I was married and already had three sons. Each time I said "baby" he gave me a puzzled look and it soon became clear that he had no idea of the total significance of the act he had drawn. He seemed to think it was like kissing. By means of several more drawings and some labored communication, he was finally made to understand the concept of conception.

The joy of knowing how babies are conceived was great fun to share. One could almost see the masses of confused ideas and hours of puzzled anguish lift.

We must be aware of the myriad of mannerisms and activities which are assimilated through the use of one's vision and hearing that either carry sexual connotations or are indicative of one's particular sex membership. Without the acquisition of these masculine or feminine traits, deaf-blind youths conduct themselves as if they were neuter beings. Being physically incapable of acquiring these traits unaided, they must be "spoon fed" the activities and exercises which normally functioning peers pick up unconsciously. Between ten and fourteen weeks, nonhandicapped children focus on the world around them and follow the movements of others. By six months a normal child begins to mimic the actions of others—learning by trial and error. If the deaf-blind child is to learn the traits that are indicative of masculinity or femininity and eventually attain sexual maturity, it may be necessary to manipulate his or her body physically in order to demonstrate the mannerisms that a deaf-blind child cannot see or hear. Other mannerisms may be tactually communicable. Still others might be better communicated by using appropriate scents along with tactual materials. For example, an adult male can make a deaf-blind boy aware of the difference in the scent of his deodorant or after-shave lotion and the scents used by females. An adult male can accompany a boy to select flowers for a female friend. An adult female can assist a deaf-blind girl in the use of bath powder, hair softener, and cologne and compare

these scented items with the scents used by males. Both male and female children can learn about the body's response to pleasurable sensation and about giving pleasure as well as receiving it through such activities as having their bodies massaged with lotion after a bath, having feet rubbed after a long hike, or helping massage a father's neck and shoulders or legs after a long day's work.

We should guide each of these youngsters in the use of grooming habits, grooming aids, mode of dress, and the use of manners which enhance sex membership. Also, we should remember the value of continual reinforcement for any behavior appropriate to the child's sex membership. With the exception of one partially seeing girl who entered the California School for the Blind from a public junior high school last year, not one of the 59 female students used any type of makeup until I made it a regular part of the growth and development lesson plan. It is not because the girls are incapable of applying makeup or because their beauty could not be enhanced by its use, but rather because many persons do not consider the application of makeup a relevant learning experience for the blind. In the cases where it is, it falls too low on the list of priorities to make it feasible. The girls who have been learning to apply makeup, including blush-on, powdered eye shadow, and lip gloss in class are all exhibiting much more positive self-images. All of these cosmetic items are easily handled with a little practice. Several of these girls are low-functioning students who will require adult supervision when they are terminated by the California School for the Blind in June, when they will have reached the age limit for attendance here.

We should be aware that a child's self-image is a basic part of his or her sexuality. Each child desperately needs opportunities for successful experiences in order to develop feelings of worth and well-being. As long as the child is unable to have those feelings, sexuality development will be at a standstill. I was amazed to discover early last year that a very small percentage of my congenitally blind students had had the opportunity to work through their feelings regarding blindness. A few had been made to feel that the word "blind" was so distasteful that they were unable to speak or braille it. Most expressed the feeling that it was very "wrong" or "bad" to be blind, giving me the impression that they had been treated as if they had chosen to do wrong by having their handicap, the way a child chooses to play in the mud wearing good clothes.

Of all the approaches taken in my classes to increase the feelings of self-worth among the students, giving them a degree of insight into the psychology of blindness had the most profound effect. The students were delighted with the idea that other people might shy away from them because the others feared blindness rather than because they felt the students were clumsy, retarded, or disgusting.

At the time, the students' feelings regarding their blindness overpowered all else. They attached little or no significance to being on the honor roll, in the Boy Scouts, or of a particular race or sex. When asked, "What are you?" their immediate response was, "Blind." Later, the responses might be, "I am a girl," "I am black," or "I am pretty."

You must make your material needs in the area of sexuality known to each other and to manufacturers of educational supplies and publishers in order to equip deaf-blind children with the tools necessary to master the complex concepts related to their sexuality. Others may have the same problems and needs as you, and together you may arrive at a solution. In communicating your needs you may find that another person has already developed a way of adapting materials or has found some other way of handling the problem. As your needs become known, appropriate teaching aids will be developed. Most of the sex-related materials available are for the normally functioning child who is free of handicaps. But just as some very exciting materials for the blind have emerged in the last two years, so shall materials for deaf-blind youth—as those needs become known.

Parent Effectiveness

Presented by Marilyn Sturrock
Parent of a Deaf-Blind Child

For the purposes of our discussion, I would like to define parent effectiveness simply as those efforts that promote the maximum development of our children who have handicaps. I sometimes feel I know little about the subject; watching my own behavior I could better be talking about parent *ineffectiveness.* But I am not going to tell you all the ways in which I have been ineffective. The list is way too long, and I am sure I would have a case of the "guilties" after I was finished. Instead, I am going to try to build on strengths and share with you what, in retrospect, I have done well.

I want to start out by saying that one of the problems of being a parent of a disabled child is the alienation we feel when we find we have a defective child. I probably expected a superbaby; possibly a future great tennis player or maybe a brilliant musician or scientist–something to do with the person I would like to have been but never could be. But I had to accept the fact that the child of my dreams never was and never would be. All parents have to accept this; we as parents of a handicapped child just have to accept it sooner. We have to allow our handicapped child to come to life like our mom and dad allowed us to do, and at the same time we have to come to terms with our disappointment. We also have to be willing to take on extra, serious demands. I consider alienation as feeling outside of things, cut off, not really understood by anyone, and I think it is a really serious problem. For myself, when I am feeling that way, I pull away from a situation and withdraw. When I do that I not only lose perspective about the situation itself, but I also fail to get the nourishment I could be getting from the outside world. I do not get the feeling of accomplishment. And I am not maintaining my self-esteem the way I would like.

We are here together partly to cope with that feeling of alienation by sharing our concerns with others who understand.

My main presentation is divided into three parts, corresponding to the stages that we go through in our development with our children. The three stages are (1) surviving; (2) coping; and (3) reaching out and creating. These periods are not distinct and they are not separate; they interrelate. At a given moment we are merely surviving; two hours later we are being creative; then we are back to coping efficiently; and so on.

Surviving

When I talk about surviving, you all know what I mean–making it from morning until bedtime and getting rested for the next day. Making it day-to-day somehow, just doing each job as it comes along, and sometimes not being able to manage that. First of all, we have to survive the impact of learning that our child is multihandicapped. I had to give up my hopes for the perfect boy of my dreams, and I had to realize that my giving birth to a handicapped child did not mean there is anything wrong with me. Collin is eleven and a half years old, and we assume he is a rubella child. He is deaf-blind and retarded and is on his way to being about six feet four inches of a very active and strong adolescent. He sleeps very little. He cannot eat by himself, and he has not yet managed to take himself to the toilet on a regular enough basis so that one can relax about it.

Collin was born the last of three children, and I found it difficult to give my other children the attention they needed. I am just now catching up on attention giving with my sixteen-year-old daughter. I recently heard a talk by a man at the Stanford Medical School who counsels parents of dying children. He maintains that the family which gains support from each other and shares feelings of fear and inadequacy can survive this very difficult situation.

One important factor in surviving is keeping up our own health. This is focusing on ourselves, of course. When Collin was born, I took up tennis. It is said that continuing stress causes illness, so I took up tennis to keep myself strong. My husband plays tennis and he had always urged me to find some kind of outdoor sport we could do together.

So I took up tennis, and in the afternoons when he came home from work we would pick up our tennis gear, our other children, and Collin in a porta-crib or infant seat and head for the tennis courts for an hour or so. Tennis served many purposes for me. It got me into the health-giving sunshine. It got me moving around and switching to a higher metabolism at the end of the day. It completely took me away from my concerns for the day so I could return home refreshed and energized. It also gave me something to do with my husband, and not the least important, it gave me an outlet for some of the anger, confusion, and resentment I was feeling in raising my children.

I still play tennis often, and it has turned into a great source of pleasure for me. I also joined a yoga group for practice in doing flexibility exercises in a very relaxed state. Those are times devoted to me.

As far as Collin is concerned, keeping him healthy and strong and resistant to all the bugs floating around is a very difficult job indeed. To accomplish this I need to be very alert to his nutrition. He is a dreadful eater and would live on potato chips and cookies and sweet drinks to wash it all down. He looks strong and healthy but he is not. If he gets a cold or the flu, he gets sick quickly. Keeping him healthy has been a major concern of mine.

I also had to find a doctor who was sympathetic and interested in his individual needs, our overall family needs, and our values. I did not find the right doctor until Collin was about three years old, and those first three years were not made easier by a doctor who was not warmly understanding. Our current pediatrician is extremely cooperative and is aware of our priorities with Collin. She takes extra time with us. She adapts to his special needs and explains herself simply. As soon as Collin begins to be sick, we phone her office and take him immediately to her. She gives him double doses of medicine to try to forestall the rapid decline in his condition. If we need to have x-rays or blood tests, she provides us with extra hands to help keep Collin still. She also has been concerned about Collin's effect on our other children and about my own health. She always tells us all the possible courses of action and lets us make the decision. She has suggested regular periods of respite for the family. She brings up considerations of placement. She helped me with Collin's eating problem and called in the clinic nutritionist. She has tried to find special ways of handling difficulties and passes them on; for example, how to cope with Collin's stuffy nose before he knew how to blow his nose. She has tried to find special medicines that might help him sleep so we could get a little sleep, and she has always looked at the health of our whole family. Having a sympathetic and knowledgeable partner in our doctor has made a big difference for us.

When Collin was two years old, we also had a home worker for the blind who suggested we try to stimulate Collin with a jungle gym. We found it was something that Collin took to and loved, and he spent many hours outdoors. I feel that working out on that jungle gym has made Collin much healthier than he would have been otherwise.

I think that when we are surviving we have to think of what our family is getting and not getting. And as I look back on it now, I wish I had gotten my family members working as a team in setting goals for Collin and working toward them—sharing feelings, both negative and positive, with each other. I wish I had gotten them to help each other in such a way that their survival was made easier. We were fortunate to have friends who were our extended family. They gave our children some of the attention and interest that I would like to have given them myself. There is no doubt in my mind that during these critical periods and especially the early periods, our children suffer and our husbands suffer, and I think they might have suffered less if I had been able to express my feelings more; in turn they also would have done so. Our two older children did feel free to express some negative feelings about Collin: anger, embarrassment, frustration, and lack of satisfaction.

Part of surviving, to me, means having someone to talk to, someone who will listen, someone who will understand. This might be a member of one's own family; it might be a best friend; it might be a community service person who comes to visit. In our case a superwoman from the Variety Club for Blind Babies came to our home once a week while Collin was a baby, and I spent hours telling her my problems.

During the period of surviving, we still have to deal with the outside world, and the outside world has its injustices, prejudices, and stigmas which it attaches to our children. We have to learn to make simple demands on society, to find people on the outside world who are willing to listen and understand. We have to present ourselves in such as way that these people can satisfy some of the needs of our children. This means talking to a lot of people, and it means being in the position of almost begging for services for our children.

At the end of our surviving period (and I think I have spent most of my hours, since Collin was born, just surviving), we have to begin to face the facts about the handicaps that our children have and what kind of future there is for them. We have to begin to face the fact that it will be a long and difficult job, one filled with difficult decisions such as whether to place our child out of our home. We may need many updates from professionals about the prognosis for our child. When I am in a surviving stage, I try to keep three aims in mind: to keep myself as calm and relaxed as possible; to refuse to let things become a bigger deal than they are; and to never be afraid to fail. Failure can teach one more than success.

Coping

When we get to the coping stage, we begin to sharpen our wits and widen our hearts. We are thinking of ways to take action that enables us to adjust to our special situation. Coping means getting things done that have to be done: finding a school for one's child, arranging for medical attention, arranging for the child to be with other children of the same age. We begin to see what the child's immediate demands are and how we can meet those needs, and we begin to explore the facilities in the vicinity that will respond to our child's needs.

When I first started looking for a nursery school or some kind of educational system, there was none in our community. At that time I had to go out and talk to various people locally in the educational system. They had never talked to a parent of a child like Collin. I talked to the persons having to do with hearing-disabled problems and the visually handicapped program in the Palo Alto City Unified School District, the children's health counsel, and counselors in the Berkeley School for the Blind, where there is a program for the deaf-blind. I talked to administrators of the Community Association for the Retarded (CAR) and convinced them to take Collin in their nursery program. It turned out that the director of the preschool program was one of the most helpful, down-to-earth, understanding and sensible women I met. There were many rebuffs and rejections during all of this exploration, and some of them were very painful, but we learn to keep asking. When painful rejections happen (and they still do, but to a lesser degree), we do not want to take our anger out on the very people who are trying to help us—the doctors, teachers, and administrators.

It is a current challenge to keep remembering how it is with the other person who for some reason is unable to help us. I find when I am able to be considerate in this way our work goes most satisfyingly. Even if we cannot accomplish our goals, we can give support to each other. Perhaps during this coping period we need someone to talk with regularly to help us handle our feelings. We may be able to do this with our doctor or our minister. Maybe we even need a therapist; somehow we need to be in a situation where we can talk about our specific problems and get some help for them. I would like to see a therapist or social worker available in the schools our children attend who would be able to spend time talking with parents and brothers and sisters. Someone might be able to come into our homes and show us how to approach the problems of toileting, feeding, crawling, dressing, and keeping our children in a normal schedule.

During this coping period we have to learn to accept all the help that is offered that is beneficial to us. I think back through the years and realize that many people offered to help me whose help I was not willing to accept. I know that there are some people who want to help, but for the wrong reasons or with inadequate knowledge or actual misunderstanding of the situation. Usually these people are not of much benefit to us, and I think that we should avoid them because, in my experience, they often make one feel worse. But there are people who are willing to lend a helping hand and can be understanding in small ways and for short periods of time. I think we should trust our judgment of who can help us and then accept their help in as open a way as we can.

We ought at this period to become a little more knowledgeable about the handicaps of our children and what can be done for them. We should begin at this time to know the legal rights of due process and equal protection of the law assured by the Constitution as it applies to our children. I think we should begin to prepare ourselves to fight for the rights and needs of our children. A new law will be in effect in July, 1976, Public Law 94-142, which is called the Education for All Handicapped Children Act of 1975. This law will make sure that we have free and appropriate education individually planned for each child in conjunction with teachers, parents, and administrators. It assures our severely handicapped children of adequate assistance. We should begin to become aware, with the amount of time that we have available to us, of programs, services, and facilities that are operating

not only in our area but also in our whole state and in nearby states in case we should want to go away for services for our children or to recommend similar programs to local authorities.

During my coping period I began to write to sources offering certain publications. For example, in our state the California Association for the Retarded sends out a monthly bulletin which keeps one up to date on all the legislative proposals or administrative decisions made in the state and what they mean to our children, and it advises us when to write to our legislators to vote for or against a particular measure.

We should also be beginning to clarify and set priorities for our children (I hope that by this time they are in some kind of educational situation). I think that we should feel free to insist that our children receive the same amount of education that normal children do, and I would like to see year-round education available for our children with emphasis on living skills that bring our children towards independence.

I think that in the coping period we begin to remember the things that we need ourselves to maintain our own self-esteem and our interest in life. I am now taking a course on self-esteem at Stanford University. Our teacher feels that the more diversified the sources of self-esteem that we utilize the better, so that if we keep participating in those activities that have given us feelings of accomplishment before, they will assist in maintaining our self-esteem. The teacher also feels that interaction with people who are understanding and appreciative is important. He goes so far as to suggest that we join structured groups in which, if we are low in energy, there are available speakers or others who give us new ideas and stimulation. He also feels that we need to develop ways of appreciating ourselves. When we reach a small goal with our handicapped child, like learning a new sign and using it consistently for one day or having a perfect day at the toilet, we need to congratulate ourselves and our families. Maybe we can even have a celebration with those who helped us achieve the goal.

Being Creative

The next stage we come to is reaching out and being creative for our children. For most of us these periods of creativeness and reaching out come when we are feeling rested and relaxed, when our self-esteem is high, our health is good, and our families are functioning well. Then we have the extra psychic energy to reach out and to try to create special solutions for our child and for others like him. During these periods I think that we search for solutions that are unique and specially tailored for the needs of our children. Right now, for example, my child is living in a nearby state residential institution. It is a very inadequate placement for him, but it is the only one available in our area. He does go to an excellent school for the multihandicapped in Saratoga to which he is bussed daily. But he has been regressing since he moved to the institution, and we have been stumped and dismayed about what we could do to change this downward trend.

This past fall we found a young man who was a teachers' aide at Collin's school last year. He has gone back to college himself and is short of funds. He now brings Collin home twice a week, on Saturdays and after school on Tuesdays, and it has made a difference to Collin. Not as much difference as we would like, but it has made a difference. It has also made a difference to me because it takes at least two of us to handle Collin. I hesitate to ask my children to give up their own activities, and I hate to ask my husband to take time off from work. I also do not like to impose on my husband on Saturdays, when he is tired and needs to rest, to take care of Collin. So the solution with George, our young teacher friend, has worked out very well. It is only a stopgap measure, and we are currently working on developing a residential facility to be used for children of Collin's school who cannot live at home. We are trying to develop a home that would be suited in philosophy, environment, personnel, and program for our special children.

Along the line somewhere I have learned to accept the disappointment that comes when proposals fail for one reason or the other. While working on our proposals, we contact many agencies and local government people, and even though our proposal does not get funded, we are hopeful that these people we have contacted know much more now about the needs of our children.

In this stage we can decide to make a commitment that caring for, promoting the development of, and being an advocate for our child is important. I have decided in my own mind that one of the main jobs in my life is to make sure that Collin is developing and finding the best services available in our area. I have also decided to keep him as near to me as I can so that I can play the watchdog. As an advocate for Collin, I have decided to talk with people and keep them educated on Collin's needs

and progress in the future. Since I have made this commitment, I find that my priorities for my own time are clear. I go to more meetings, I spend more time educating myself, and my commitment has become a continuing focus for my life. I spend more time talking with other parents, teachers, and administrators for the deaf-blind. I am also considering Collin's future in trying to prepare myself for future problems. Right now I am very concerned about Collin's sexual involvement—finding an appropriate outlet for him that is not frightening to others. I am concerned about prevocational training, and I am concerned about what he will do with his time after he is twenty-one.

At the times that we are reaching out and being creative, we may also feel great pleasure at seeing that our child excels at something. Collin is the star swimmer at our local pool for the handicapped, and I sit on the board of this pool. He does not use the proper form but he swims like a dancer, grinning ear to ear. He is so happy with his movements he makes others happy watching him. Collin can do things on a jungle gym you would not believe. He can go to the top rail and swing upside down holding on with just the toes of one foot. He can also stand on his head without using his hands.

I also work at keeping Collin lovable and he does the same for me. Because I believe that most of his hours of his life he will be dependent on the good will of others, I try to fight for his dignity. I insist that people call Collin by his name. I see that he wears his own clothes and keeps a nice haircut. I try to make his life as normal as possible with regular vacations, summer camp, and holidays, too.

At the times that we are reaching out and being creative, our tough situation becomes a rich experience. We want to face our situation and deal with it in a creative way. Underneath the challenge is the belief that none of us can experience life fully until we have solved certain painful problems which have been thrust upon us without warning or preparation. We feel as if we have been challenged to work at getting our own thinking straight about our disabled child; to seeing in our own child the same urges as we have—human urges—for joy, success, and acceptance; to keep on trying for the healthy reorganization of our own family so that our special child can be part of it; and to work on organizing with others with interests like ourselves the tackling of society's long-standing problems and unfair prejudices. We feel that we are in the position of somehow understanding more of life, and finding greater appreciation and tolerance of the people we meet. We get great satisfaction out of small gains. We realize when we have talked to someone who does not know anything about our kind of child that we have broadened this person's outlook, maybe just a little bit. We get involved with other groups who are working to understand what it is like to be handicapped. At Stanford there is a group of students who get credits for studying the meaning of being handicapped. My husband has been a sponsor of the course, and we have gotten great pleasure in watching the young people broaden their compassion. And they appreciate people like us who are willing to share our personal experience.

It is not very often that I feel I am in this period of creativity and commitment. But I do know that I feel this way when I take on new challenges or when I serve on a new board or help in constructive activities that are going to make a difference to children like Collin. I have to be very careful to take on jobs where I can learn and enjoy serving at the same time. I have to remember not to reach out too far or I could fall flat on my face. During this period I have gone more into the study of philosophy. Some of you may have done the same, or possibly you have looked to your religion for reexamination of your values and meaning. My study of philosophy gives me distance from my life. I look at my life and say Ah ha! There's Marilyn down there doing such and such. And I can ask myself as a detached observer whether it is worth doing and whether it is good for Marilyn. As I look at it from that perspective, I think my awareness is very much worthwhile. It is my life's job for my child and for myself.

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